Hurdles In Achieving Registry Certification, 1995-1997

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NAACCR has had an annual Call for Data for the purpose of evaluating, aggregating, interpreting, and publishing incidence data from member registries. NAACCR developed a formal process of registry certification. The NAACCR Registry Certification Committee evaluates population based cancer registries on established objective criteria in the areas of completeness, quality and timeliness. Registries that are certified are defined as having high quality data. Since the first publication in 1992, the NAACCR definition for high quality data has evolved and become more objective and rigorous (see Appendix A).

The NAACCR *Call for Data* has three primary objectives: 1) to increase participation by all NAACCR member registries in the Cancer in North America (*CINA*) monograph; 2) to increase the number of registries included in the section of combined rates for the U.S., Canada, and North America (which is reserved for registries with high quality data); and 3) to measure data quality and set data quality standards while increasing, at the same time, participation and inclusion in the monograph. Table 1 shows the number registries from the U.S. and Canada that have met these three objectives from 1992 to 2001.

Table 1. Number of Registry Submissions to NAACCR and Number Meeting Standards for High Quality, 1992-2001

Year of Publication	No. High Quality Data	Submissions
1992	25 (all)	25
1993	26 (all)	26
1994	34	47
1995	31	48
1996	36	51
1997	19*	42
1998	28	52
1999	33	54
2000 (2)**	34	62
2001	38	61

*Canadian data were not included in the NAACCR 1997 combined data set because not all required quality assurance steps were performed.
**Two data submissions were called, and 1992-1996 and 1993-1997, to reduce the lag time in submissions by one year.

In 2000 the CINA editors formed a data quality assessment workgroup. The data quality assessment workgroup had two objectives: 1) identify the problems that registries face in meeting NAACCR high quality data standards; and 2) provide individualized feedback on data file submissions to NAACCR.

Methods

Two phases were designed to meet the objectives of this study. In phase I, informal interviews were conducted with registries and in Phase II, these registries and a set of comparison registries were contacted by telephone and asked to complete a more formal assessment tool. The assessment tool was based on information gleaned from the Phase I interviews described below. Twenty-four registries (21 in the U.S. and 3 in Canada) were interviewed during Phase I. In Phase II, an additional 10 registries were interviewed in the comparison group. The comparison registries were selected based on achieving gold certification status and meeting a quota of small, medium, and large registry participation.

Phase I

The objective of Phase I was to identify the problems that registries face in meeting NAACCR high quality data standards. We created a matrix of the data quality indicators from the 1997 to 2000 NAACCR *Calls for Data.* The matrix included registries that had not met the quality criteria in 2000 to be included in the NAACCR Combined rates (see Appendix A for combined, CINA criteria). The indicators on the matrix were percent of death certificate only (DCO) cases, percent of case completeness, rate of duplicate reports, and percent EDITS errors. Open-ended questions were used (see Appendix B), in the telephone interviews. Twenty-four registries met the following criteria for inclusion in Phase I:

- Submitted data to *CINA* and
    - were never included in the NAACCR combined rates section,
    - made dramatic improvements in recent years; or
    - data quality appeared to be declining in recent years.

Registries were grouped by the data quality indicator that precluded their inclusion in the NAACCR Combined Rates, i.e., high percent of death certificate only cases, low percent of case completeness, high rate of duplicate reports, and high percent of EDITS errors. Registry contacts were asked specific questions regarding the data quality indicator of interest. Registries were categorized into one or more of the following groups:

Group One included registries for which the data quality indicator in the 2000 *Call for Data* did not meet the high quality data standard. The following is an example of a question for this group:

> "Have you implemented any new procedures or operations to try to improve the rate?"

Group Two included registries that had a dramatic drop in the death clearance rate from 1997 to 2000. They were asked to describe any specific processes that were implemented to improve their DCO rate.

Group Three included registries that had never conducted the data quality assessment. The following is a sample question for this group:

> "According to the results from last year you did not do_____. "Have started this year?" "If yes, how did it go?" "How are you doing?"

Group Four included registries that had not improved their rate of duplicate reports. The following is an example of a question for Group Four.

> "According to our results from the calls for data from the past 4 or 5 years, your duplicate rate has not changed and it is quite a bit higher that the standard." Do you have any ideas as to why it persists?"

In addition, each registry contact (respondent) was asked about issues of case completeness from hospitals and activities related to death clearance and non-hospital reporting.

After the interviews, interview summaries were prepared.

Phase II

Based on the results of Phase I, we developed a tool to assess the hurdles identified by the registry directors (see Appendix C). Each registry director was contacted a second time. Ten additional registries were also selected to act as a reference for high quality. They were chosen based on receipt of gold registry certification for 1997 or 1998 data.

The assessment tool included questions on the number of full-time equivalents (FTEs) in their registry and on the following 6 registry operations: 1) case reporting; 2) log-in and verification; 3) record editing; 4) record linkage; 5) death matching; and 6) record consolidation. The assessor ranked each registry operation from 1 to 5 with 5 being the highest (meaning totally computerized, no manual effort).

In addition, the timing during record processing of when computerized editing was conducted was assessed. To help NAACCR identify interest in future training, questions were also asked about interest in a workshop on evaluating registry processes, the NAACCR mentor fellowship program, and having a mentor identified for their registry.

From other sources, information was extracted on the age of the registry, annual case load size, and registry certification status for 1997 and 1998. Registries were categorized by their annual case load as follows; small was defined as less than 10,000 cases; medium was 10001 – 34,999 cases; and large was 35,000+. The medium and large categories were combined due to small numbers in each category that prevented a meaningful analysis.

Phase II Analysis

Three analytic questions were addressed. The first evaluated registry certification status by registry resources. The variables included in this analysis were certification status for 1997 and 1998; registry size (number of cases); initial operation year; year became population based; number of records; number of FTEs; and number of records per FTE. The second question explored the relation of the extent of computerization of operations and certification status. This analysis included the following information collected in Phase II on computerization of case reporting; log-in and verification; record editing; record linkage; death matching; and record consolidation. The last question evaluated the timing and number of times edits were run and its relation to registry certification status for 1997 and 1998. Each of the edit runs were assessed individually and then a composite score of the total number of steps that included computerized editing was developed. Each step was assessed on the timing on the edit run, i.e. at the hospital; on submissions; when editing new records; at the close of the year; and on files prepared for users. Each registry contacted was asked the number of times EDITS was run on files throughout the year. The computerized edits composite score was compared by registry certification status.

Analysis of variance and contingency table analysis were used to determine the significance of a relationship between any of the variables and registry certification status. Results were considered statistically significant with a two-sided P-value of 0.05 or less.

Results

Phase I

Twenty-four registries were interviewed. Common themes for insurmountable hurdles were identified: personnel shortage and need for mentoring or training. However, some hurdles were difficult to identify and thus no direction for future improvement could be found.

Registries that did not run EDITS cited that the EDITS program was too difficult, hardware was inadequate for running the EDITS program, or the lack of staff expertise to run the program. Registries that were asked about their high duplicate record rate reported that their rate was high for the following reasons: the registry had a higher priority, (e.g. case completeness), the registry had its own procedure to ascertain duplicate reports, or the registry had a shortage of personnel. The reported reasons for low case completeness were delays in hospital reporting, lack of legal authority for non-hospital reporting, or lack of routine monitoring of case reporting from individual facilities. The registries that did not conduct death clearance cited the following reasons: shortage of personnel or a higher priority activity, such as case completeness. The reason for a high percentage of death certificate only cases was attributed to flaws in registry matching programs, delays in hospital reporting, or late starts in death clearance processes.

Phase II

Data from thirty-four registries were successfully gathered using the assessment tool and compared with registry certification data for 1997 or 1998.

Table 2. Relationship of Certification Status for 1997 and 1998

	1998		
1997	**Yes**	**No**	**Total**
Yes	82.4%	17.6%	17
No	23.5%	76.5%	17
N	18	16	34

Relationship of Certification Status for 1997 and 1998. Table 2 shows that about 82 percent of registries certified for 1997 data were also certified for 1998 data, while about 77 percent of registries not certified for 1997 data were also not certified for 1998 data. There was a significant association, $X^2 = 11.8$, $p < .001$, between certification status for 1997 and 1998 data, as one might expect.

Table 3. Registries that Improved Certification Status for 1997 and 1998

Change	Reason
Gold from not certified n=2	Completeness, race and Death Clearance
Gold from silver n=2	EDITS and Death Clearance

Registries that Improved Certification Status for 1997 and 1998. Table 3 demonstrates that four registries that were not certified for 1997 data did become certified for 1998 data. Two registries changed from no certification to gold certification due to improvements in either the completeness of race data or a lower DCO rate. Two registries

improved from silver certification status for 1997 data to gold for 1998 data by achieving the high quality data standards for either the EDITS error rate or the percent of DCOs. No registries changed to a lower certification status from 1997 to 1998.

Table 4. Relationship of Registry Size and Certification Status for 1997 and 1998

	Size	
Certification	**Small**	**Not Small**
1997	35.3%	64.7%
N	6	11
1998	39.0%	61.0%
N	7	11

Relation of Registry Size to Certification Status for 1997 and 1998. Table 4 demonstrates that about the same percentage of registries for either 1997 or 1998 data were certified regardless of registry size.

Table 5. Relationship of Mean Registry Initial and Population-based Year and Certification Status in 1997 and 1998

	1997			1998		
	Yes	**No**	**P <**	**Yes**	**No**	**P <**
I Mean	1975	1980	.033	1976	1980	0.41
N	17	17		18	16	
P Mean	1982	1984	0.59	1982	1983	0.67
N	17	17		18	16	

I= Initial Year P= Population-based

Relationship of Mean Registry Initial and Population-based Year and Certification Status for 1997 and 1998. Table 5 shows that the mean initial year of operation for a registry that was certified for 1997 data was 1975. It was 1980 for those registries not certified for their 1997 data. The mean year a registry had population-based data available for a registry certified for 1997 data was 1982 and it was 1984 for a registry certified for their 1998 data. No association was found between a registry's initial operation year and certification status for either 1997 or 1998. The year population data were available was also not associated with certification status for either 1997 or 1998 data.

Table 6. Relationship of Case Load and Certification Status for 1997 and 1998						
	1997			1998		
	Yes*	No	P <	Yes*	No	P <
Mean Case Load	20,222	21791	.83	23,447	18,261	.49
N Registries	17	17		18	16	
*Omits one Outlier						

Relationship of Case Load and Certification Status for 1997 and 1998. Table 6 shows that the mean case loads did not significantly differ by certification status in either 1997 or 1998.

Table 7. Relationship of Number of FTEs and Certification Status for 1997 and 1998						
	1997			1998		
	Yes	No	P <	Yes	No	P <
Mean	10.6	11.0	0.93	11.9	9.7	0.59
N	15	16		16	15	

Relationship of Number of FTEs and Certification Status for 1997 and 1998. Table 7 shows that the mean number of FTEs for registries that were certified for 1997 or 1998 data were not significantly different.

Table 8. Relationship of Case Load per FTE and Certification Status for 1997 and 1998						
	1997			1998		
	Yes	No	P <	Yes	No	P <
Mean	1,885	2,149	0.66	2062	1979	0.89
N	15	16		17	15	

Relationship of Case Load per FTE and Certification Status for 1997 and 1998. Table 8 demonstrates that the mean case load per FTE for those registries that were certified for 1997 and 1998 data were not significantly different.

Table 9. Relationship of Computerization of Registry operations and Certification Status for 1997 and 1998

Computerization		**1997**			**1998**		
		Yes	**No**	**P <**	**Yes**	**No**	**P <**
Case Reporting	Mean	3.9	3.9	0.92	4.1	3.8	0.24
	N	16	16		17	14	
Login	Mean	3.5	3.9	0.21	3.4	2.7	0.22
	N	16	15		17	14	
Editing	Mean	3.5	2.7	0.48	3.5	3.7	0.56
	N	16	15		17	15	
Record Linkage	Mean	3.8	3.8	0.89	3.9	3.8	0.84
	N	16	15		17	14	
Death Matching	Mean	3.2	4.0	0.05	3.5	3.7	0.75
	N	15	14		17	12	
Record Consolidation	Mean	2.9	3.7	0.04	3.1	3.6	0.14
	N	16	15		17	14	

Relationship of Computerization of Registry Operations and Certification Status for 1997 and 1998. Table 9 shows that the mean level of computerization for registry operations was not significantly different for certification status for 1997 data, with the exception of death matching and record consolidation. No associations were found between registry operations variables and certification status for 1998 data.

Table 10. Relationship EDITS and Certification Status for 1997 and 1998

Timing of EDITS…		**1997**			**1998**		
		Yes	**No**	**P <**	**Yes**	**No**	**P <**
…sent to hospital	%	55.6	44.4	0.48	**66.7**	**33.3**	**0.08**
	N	10	8		12	6	
…on submissions	%	41.7	58.3	0.10	54.2	45.8	0.84
	N	10	14		13	11	
…add new records	%	48.3	51.7	0.54	55.2	44.8	0.47
	N	14	15		16	13	
…make user files	%	56.5	43.5	0.24	56.5	43.5	0.54
	N	13	10		13	10	
…at close of year	%	50.0	50.0	1.0	53.3	46.7	0.93
	N	15	15		16	14	

Relationship of EDITS Timing and Certification Status for 1997 and 1998. No associations were found between timing of EDITS and certification status for either 1997 or 1998 data.

Table 11. Relationship of EDITS Frequency and Certification Status for 1997 and 1998						
		1997			1998	
	Yes	No	P <	Yes	No	P <
Mean	3.8	3.9	0.89	4.1	3.6	0.31
N	16	16		17	15	

Relationship of Frequency of EDITS Runs and Certification Status for 1997 and 1998. The mean frequency of EDITS processing was about the same regardless of a registry's certification status for 1997 or 1998 data.

All 34 registry contacts stated they would be interested in a workshop on methods to help manage processes more efficiently, apply for a NAACCR Mentor Fellowship program, and have a mentor registry, matched in caseload size, that had achieved certification for their own consultation.

Discussion

The data suggested that achievement of national standards for data quality was not related to registry size, age, extent of computerization, extensiveness of using registry computerized edits, or caseload per FTE workload. However, the study did not include indicators for the qualification of staff (e.g., number of CTRs), and this may be a better measure of workload.

Further, it may be useful for future assessments to include process measures so that an evaluation of the efficiency of operations could be assessed. Inefficiencies in operations does impact perceptions of being short-staffed, over-worked, and a real inability to perform all necessary registry operations to produce high quality data. If inefficient operations could be made more efficient, then it is possible that staff and resource shortages will be eased.

This study only includes registries that have participated in the NAACCR *Call for Data*. Registries that have not yet participated (5-7 in any recent year) may have different hurdles, including hurdles that may prevent participation. Second, the assessment did not include measures for staff mix, i.e. the mix of skill sets needed to run a complex program like a cancer registry. Future studies should include these variables in the design.

Recommendations

A workshop on assessing the efficiency of registry operations might be useful, using a Six Sigma or Total Quality Management, TQM, Approach. TQM is defined as the process of quality or a corporation-wide belief that everyone in the organization is responsible for assuring that every step or activity of the organization is subjected to improvement in the level of excellence[1].

[1] Hutchison, CL, Roffers SD, Fritz, AG. Cancer Registry Management Principles and Practice. Lenexa, Kansas: National Cancer Registrars Association, Inc., 1997.