



Evaluating and Addressing the Needs for Central Cancer Registry (CCR) Data Collection



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Introduction

In recent years, many changes and new elements have been introduced to the CCR data collection process. Changes and complexity have led to missing/incomplete data elements; delays in responding to research requests; and concerns about quality of some data elements. CCR data collection includes, at a minimum, data on demographics, tumor characteristics and treatment from diverse sources. A common, identified and standardized set of data elements is needed to make data available quickly and efficiently for public health, surveillance and research.

Objective

Develop and administer a questionnaire for CCRs to 1. identify data needs and barriers for public health surveillance and research; 2. assess completeness of data collection and quality of data elements.

Methods

We conducted a systematic review of the literature; looked at long-term and newly-required data elements; and developed a questionnaire. The instrument contained eight topic areas: 1. Research; 2. Data collection; 3. Database/ repository; 4. Use of data; 5. Additional data items; 6. Data requests; 7. New data fields; 8. Cancer Registry Data Set. We identified CCRs through the NAACCR directory and emailed each CCR with a direct link to the survey instrument (Survey Monkey).

Results

Of the 51 CCRs contacted, 43 (84%) responded to all or some of the questions. (see Tables)

- CCR data are used for public health surveillance (100%) and research (96%).
- Data are available online in interactive tables for over 50% of CCRs;
- 87% have more than 10 years of data available.
- CCRs report that treatment data are not complete but are of high interest to data requestors.
- Over 70 % report there are too many required data.

Results

Table1: Cancer Registry Region and Type

Survey Item	N	Response
In which geographic region is your registry located?	41	
		Northeast 11 (27)
		Midwest 12 (29)
		South 10 (24)
		West 8 (20)
Where is your registry located?	35	
		State Health Department 23 (66)
		University 12 (34)
		Not sure 0

Table 2: Cancer Registry Responses Data

Requests	Survey Item	N	Response		
			Yes	No	Not sure
Can you fill data requests the cancer registry receives?		22	6 (27)	(68)	1 (5)
If you cannot fill all data requests, specify the reason(s)?		12			
	Data elements are not collected		12 (100)		
	Data elements are not available		5 (42)		
	Data elements are not reliable		7 (58)		
	Date elements are not complete		8 (67)		
	Date elements have missing /unknown value		4 (33)		

Table 3: Cancer Registry Data

Survey Item	N	Responses		
		Yes	No	Not sure
Cancer registry data and availability				
Do you receive updated information on vital status and tumor status for each case?	22	15 (68)	7 (32)	0
Do you make the cancer registry data available for data requests?	22	22 (100)	0	N/A
Are registry data available online in interactive tables?	22	13 (59)	9 (41)	N/A
Can you fill all data requests the cancer registry receives?	22	6 (27)	15 (68)	1 (5)
Do you consider NAACCR silver certification as research quality data?*	20	14 (70)	6 (30)	N/A
Are you interested in additional data items or elements that are not mentioned. If yes, what additional data items are you interested in?	22	3 (14)	19 (86)	N/A

Discussion/Conclusion

Cancer registration is a rapidly changing field. Basic questions remain: What data elements are needed for what purpose and what are the common elements? By constantly adding data elements, are we getting too specific versus complete? Can treatment data be of value if the fields are incomplete? Data that are collected by CCRs are most beneficial for data analysis and research, public health and surveillance when data are accurate, timely and complete. Cancer registries have data available for use but need to review what data are needed/used and build collaborations/partnerships to connect common interests and increase accessibility.