# NAACCR

# Assessment of Central Cancer Registry Timeliness and Reporting Standards Task Force (ACCR TRS TF)

## Final Report to S&RD Steering Committee

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## **Executive Summary**

Although most central registries require that cases be reported to them within a prescribed timeframe (usually within a few months of diagnosis), data are not submitted to standard setters for national surveillance statistics until 14- to 23-months after diagnosis. After submission, statistics are delayed for another 5 months before data are publicly available. In total, there is more than a 2-year lag in between the end of a diagnosis year to publication of cancer statistics. The Assessment of Central Cancer Registry Timeliness and Reporting Standards Task Force (ACCR TRS TF) was formed when real-time reporting was identified by the NAACCR membership at a Registry of the Future session in Ottawa, ON, Canada in 2014 and set as a priority activity at the NAACCR Board-Chair Meeting in Miami, FL 2015. The overall goal of the TF was to examine whether the cancer registry community should consider changing its timeliness standards and determine barriers and challenges to collect data earlier and identify opportunities that might help improve timeliness of cancer reporting.

Over the last two years, the ACCR TRS TF:

- Conducted key informant interviews;
- Analyzed 12-month data submitted to NAACCR in collaboration with the 12-Month Data TF;
- Conducted a survey of US and Canadian registries with a 70% response rate (51/73);
- Hosted 4 telephone-based focus groups with 11 US registries to collect more detail on early use of registry data, strategies used to improve timeliness, and considerations toward a two-tier reporting system; and,
- Evaluated data at 13 central registries through a coordinated approach that allowed registry staff to conduct the analysis onsite and report aggregate statistics to the TF.

#### Salient Findings

Improving the timeliness of cancer surveillance data is an often-debated issue in the NAACCR community. Our research shows that registries are divided into three groups:

- Those that believe that cancer registries can meet current timeliness standards and there is no need to change current operations;
- Those that believe that improving timeliness is feasible, and, therefore, we should continue to advance this initiative; and,
- Those that believe that improving timeliness is something that the cancer surveillance community should continue to pursue, but registries lack the financial, human, and technological resources to change the process.

Most registries require that cancer data be reported to central and regional registries within 6 months of diagnosis. Although only about half (46%) of registries reported that surveillance data are submitted according to state reporting requirements, 77% of registries who responded to our survey stated that they are implementing, evaluating, or considering initiatives to

improve timeliness, including expansions in electronic reporting and routine feedback to hospitals.

Generating more current cancer incidence rates has been one of the arguments for improving timeliness. However, to use the data early, two-thirds of registries who responded to our survey stated that data had to be at least 90% complete before it can be used. Fortunately, 12-month data has been shown to generate reliable cancer incidence statistics for many cancer sites with appropriate delay-adjustment [1-3].

Our data further suggest that registries may be closer to having complete data than they think. For each registry that participated in our analytic study, the top 10 cancer sites accounted for nearly 75% of all cases for their state/region; and, 88% of melanoma, 84% of colorectal, and 82% of breast cancers were surgically treated and, therefore, complete data including stage could be derived in a timely fashion. Other evidence suggests that 12-month NAACCR data are generally 80% complete and of better quality due to the type of reports that are used to create incidence records. Based on focus group responses, registries will postpone the creation of a cancer case until a full NAACCR abstract is received. This process often delays the creation of a case from other sources that may have been reported earlier (e.g., HL7 e-path records).

Indeed, the ability to process early (and potentially incomplete) data is one of the most often cited barriers to advancing timeliness. Evidence from the survey as well as the focus groups suggests that information systems are not able to process NAACCR Modified Records in an accurate and efficient way, with most registries updating registry data manually. Given this significant gap in consolidation routines, registries are hesitant to create new cancer incidence records based on incomplete case reports that would have to be "updated" or "modified" with subsequent records and are ill-prepared to implement a two-tiered reporting system. Prior studies have found that resubmissions from hospitals to central registries after 15-months have resulted in improved data, but they also found that updates are in fact feasible and could be implemented [4-6].

Although barriers and challenges have been expressed by registries, we found that 36% of survey respondents were in favor of changing reporting timelines for research purposes. In focus groups, we found that registries used data early for rapid case ascertainment studies and clinical trials, the CDC's early case capture project, cancer cluster investigations, and some are used to generate preliminary incidence statistics. Early use of data was also limited to specific demographic and tumor fields and excluded treatment and stage. The CoC's Rapid Quality Reporting System (RQRS) tool was also recommended by some registries as a possible resource for real time data, however, the frequent changes to reporting requirements may hinder this effort as hospital registrars struggle to keep up with new and revised coding guidelines, staging variables, and additional data requirements.

#### Recommendations

• Stabilize cancer data standards so that registries can focus on improving timeliness.

- Improve software tools to enable registries to accept early incidence reports, which may have incomplete or preliminary data, and to auto-consolidate data to decrease manual review and editing by registrars.
- Develop guidelines with central registry processes that improve their timeliness, providing feedback to hospitals and other reporting facilities, and determining minimum/core data elements for an early incidence report.
- Evaluate how central registries can leverage the RQRS system to enhance reporting.
- Work with central registries to determine feasibility of shortening reporting requirements to less than 6 months (4 months or 2 months), understand resource constraints to process multiple and potentially more frequent reports for each case, and evaluate resources needed to revise statutory reporting requirements.
- Develop an ongoing NAACCR process to monitor the quality and completeness of 12month data reported by central registries in the Call-for-Data, including metrics for which improvements can be measured.

#### I. Background

- a. Motivation Real-time reporting was identified by NAACCR membership at the Registry of the Future session (Ottawa, ON, Canada 2014) and set as a priority activity at Board-Chair Meeting (Miami, FL 2015)
- b. Goals/Objectives Goals were to define "real-time reporting" and propose strategies to enhance timeliness of cancer reporting. To meet these goals, we set out to achieve the following objectives:
  - 1) Delineate differences between "real-time reporting," "rapid case ascertainment," "early case capture," and "timely reporting";
  - 2) Determine potential costs and benefits to more rapid reporting; and,
  - 3) Determine barriers, challenges, and opportunities to improve timeliness of cancer reporting.
- c. Strategies Several strategies were implemented to complete the above objectives. Each are detailed below.
  - 1) Key informants were engaged to discuss rapid reporting (Colleen Sherman, Steven Peace, and Serban Negoita). Several of the initial task force meetings included discussions about what might be considered "real-time reporting" vs. "timeliness"; and, important considerations around workflow, resources, and data quality. The task force also invited key informants to learn about the CoC's RQRS system (Catherine Bieker andSilvia Sandoval, RHIT, CTR, Registry Manager, SCL Health Cancer Registries) to ascertain what might be leveraged for rapid reporting to central registries; and, we invited members of the 12-Month Data Task Force as we realized that there might be useful information about the quality and utility of 12-month data submitted to NAACCR.
  - 2) Survey An online survey of central cancer registries across North America was conducted from May 9-25, 2015. The goal of the survey was to determine barriers, challenges, and opportunities to improve timeliness of cancer reporting. The survey included questions covering four areas: registry characteristics, incidence reporting, timeliness, and data quality and completeness. The final survey is included in <u>Appendix A</u>.
  - 3) 12-Month Data Since NAACCR requested 12-month data in recent years, the Task Force collaborated with the 12-month Data Task Force lead by Frank Boscoe (NY) to evaluate the quality of 12-month data and consider how these data might inform the discussion around where registries currently stand in terms of 12-month data.
  - 4) Special Study Most central registries require that cases be reported to them within a prescribed timeframe. Six months from the date of diagnosis or date of first contact with the patient seems to be common standard among registries. This standard made sense in the days when cancer treatment was most often initiated and completed within six months of diagnosis. The six-month reporting delay was by design so that

registries could receive complete case reports and not have to be concerned with collecting treatment information in a piecemeal fashion. However, current first-course treatment regimens can begin as long as 18 months after diagnosis. If registries choose to adhere to the same philosophy of wanting only "complete" case reports, we are forced to wait varying lengths of time to receive case reports due to the nature of how cancer care is delivered. This strategy presents problems in tracking completeness and having complete, population-based data in a timely manner.

This TF is examining whether the cancer registry community should consider changing its timeliness standards and perhaps changing the philosophy of requiring "complete" initial case reports. Before we can determine if cancer registration practices could change, we must first understand the characteristics of the cases we register. The primary goal of this analysis was to understand more about what proportion of cases in a central cancer registry *could* be reported more rapidly because an incidence record *should* be complete within a relatively short period of time.

Most central registries still receive the majority of their case reports from hospitals. For those registries whose catchment area includes a significant proportion of Commission on Cancer-accredited programs, the Rapid Quality Reporting System of the CoC may be affecting how and when cases are submitted to the central registry and how complete cases are when they are first submitted. RQRS is a requirement for CoCaccredited programs as of January 2017. RQRS is discussed in more detail elsewhere in this report.

5) Focus Groups – Focus groups were conducted to determine barriers, challenges, and opportunities to improve timeliness of cancer reporting. TF members sought to follow-up on specific issues identified in the survey that required more detailed information and might benefit from a more thorough discussion into registry approaches to improve timeliness and to document the challenges that remain.

#### II. Key Informant Interviews and Task Force Discussions

#### a. Definitions

- 1) Real-time:
  - the *actual time* during which a process or event occurs; or,
  - a system in which input data is <u>processed within milliseconds</u> so that it is available virtually immediately as feedback; or,
  - at once or <u>instantaneously</u>.
- 2) Timely:
  - <u>occurring at a suitable time</u>; opportune; well-timed; or,

- early or soon; or
- done or occurring at a favorable or *useful time*.

The utility of either real-time reporting or timely data was further considered in the context of central registry data flow (see Figure 1. Timeliness Continuum). As depicted in Figure 1, there are several points during the data flow process where time delays are embedded and where specific processes such as "rapid case ascertainment" that require real-time data separate and apart from the usual cancer surveillance reporting process.



b. RQRS – The CoC/ACoS has implemented a Rapid Quality Reporting System (RQRS), which is a web-based reporting tool that CoC-accredited hospitals are using to provide "real clinical time assessment of hospital level adherence to quality of cancer care measures." (https://www.facs.org/qualityprograms/cancer/ncdb/qualitytools/rqrs). Registrars are required to prospectively enter core data about the patient and his/her cancer diagnosis along with treatment data. RQRS is set up as an "alert system" for cancer programs when specific treatment or quality care metrics are due. The overall goal of this program is to ensure that patients receive guideline concordant care and eventually improve outcomes. To central registries, the advantage of the RQRS system is that it serves as an early case capture or tiered reporting system whereby base or core incidence data are coded to create an initial record and treatment data are entered later in time as they occur. One challenge that was identified is the demand on staff time to continuously update the RQRS record as changes or updates are required. Caveats to this system is that the RQRS tool is not available for all cancer sites (only breast and colorectal) and it is not used at all CoC facilities.

- c. Important Considerations Key informant interviews also provided important considerations that impacted the direction of the TF. Namely, TF members were advised to consider timeliness in the context of (1) registry resources and challenges to maintain current requirements by standard setters; (2) what will be gained by collecting real-time data or more timely data; and, (3) who will benefit from the early data. Questions around what type of data might be collected early was also discussed.
- III. Survey Findings presented at 2016 NAACCR Annual Conference, June 14, 2016, in St. Louis, MO. A follow-up presentation was conducted via webinar on September 29, 2017.
  - a. Methods Central registry representatives were invited to participate in the survey via email (NAACCR listserv). Although we expected to receive 1 survey per registry, registries were free to consult with staff with specific expertise to answer questions. Therefore, responses to specific survey questions may have been derived from a number of registry respondents. Survey data were collected via SurveyGizmo. Open-ended text questions were reviewed by Task Force members and key themes identified and summarized. The final survey is included in <u>Appendix A</u>.
  - b. Results
    - Response Rates A total of 73 registries were invited to participate in the survey. A total of 51 (70%) completed the survey and 6 were partially completed.
    - 2) Registry Characteristics There were a total of 46 US and 8 Canadian registries and 50 state/provincial and 4 regional registries. Nearly 30% of respondents were registries with fewer than 10,000 cancer cases per year. Not surprisingly, most (67%) required reporting within 6 months of diagnosis, but as many as 15 registries stated that reporting was required within 1-2 or 4 months of diagnosis or that reporting requirements varied depending on the source facility. Fifty-one percent (n=23) of 45 US registries received more than 75% of their data from CoC-approved facilities and an additional 15 (33%) received between 50-75% of their data from CoC-approved facilities. When asked if registry database management systems could accept NAACCR modified records, most registries (n=38/54) said yes. However, many of these registries (n=14) process these records using a combination of manual and automated consolidation routines. Six processed these records using automated

processes exclusively, but 11 registries still use manual processes exclusively.

3) Timeliness – About 71% (38/53) of registries did not have two-tiered reporting processes. However, some registries that did report two-tiered reporting (n=14) considered the receipt of electronic pathology reports as "tier 1" and the subsequent NAACCR record as "tier 2" (n=5) and others reported the CDC Early Case Capture project as a two-tiered reporting process. When asked what variables were required as part of "tier 1," 100% of registries reported that the patients' name and sex were required. However, requirements for other variables such as date of birth, address at diagnosis, primary site, histology, and SSN varied (see Figure 2).



When asked if specific electronic reporting mechanisms were utilized (i.e., CAP checklist, electronic case finding, participation in HIE), few registries stated that they had implemented these in their standard registry operations. In fact, nearly 30% of the 53 registries that responded to this question said that they had no plans to implement CAP checklist protocols, and only 12 registries stated that they actively use electronic case finding processes with hospitals, pathology labs, and physician offices. In contrast, slight more than 20% of 38 respondents stated that they were planning to implement HIE data sources into operations.

4) Timeliness – When asked if registries use their data early (i.e., before data submission to NAACCR and other funding agencies), 24 of 53 (45%) reported that they do: (a) 22 registries use the data early to monitor and evaluate reporting patterns (15 within 12 months of diagnosis); (b) 18 registries use the data early to generate incidence statistics (8 within 12 months of diagnosis); (c) 12 use the data as part of early case capture for surveillance (9 within 6 months of diagnosis); and (d) 17 use the data as part of rapid case ascertainment protocols for research (10 within 6

months of diagnosis). To use the data early, 14 of the 21 respondents stated that data had to be at least 90% complete to use. When asked if registries should change timeliness standards, overall about 30-40% were undecided. When asked if timeliness standards should be changed for specific purposes, responses varied. Changing reporting timelines for reporting facilities was split (33% Agree/Strongly Agree, 33% Disagree/Strongly Disagree). Changing reporting timelines for central registries to report data to NPCR/CDC/Statistics Canada leaned toward disagreement (25% Agree/Strongly Agree, 37% Disagree/Strongly Disagree). Similarly, changing reporting timeliness for NAACCR submission also leaned toward disagreement (21.5% Agree/Strong Agree, 39% Disagree/Strongly Disagree). More registries agreed with changing reporting timelines for research (36% Agree/Strong Agree, 26% Disagree/Strongly Disagree). Nearly all registries stated that changing reporting timelines would require changes to registry operations (94%) and the current model of cancer surveillance reporting (80%), and 67% (n=34) stated that it would also require a change to state reporting statutes and regulations. When asked if their registry was implementing new initiatives to improve timeliness, 23 of 53 (43%) said yes and an additional 18 said they were assessing options and would like to consider initiatives (see Figure 3).

Registries cited e-path expansion, follow-back and routine progress reports to hospitals, instituting a state certification program for hospitals who meet reporting requirements for the state, improving physician reporting through Meaningful Use transmissions, implementing early case capture, and integrating rapid case ascertainment into registry

Value	Percent	Count
Yes	26.4%	14
Yes, but in feasibility, planning or development phase	17.0%	9
No, but assessing options and would like to consider initiatives	34.0%	18
No, and no plans to do so	17.0%	9
Don't Know	5.7%	3
	Total	53

Figure 3. Is Your Registry Implementing New Initiatives to Improve Timeliness?

operations as current initiatives. Registries who stated that they are not considering new initiatives to improve timeliness, cited lack of resources, they were already meeting requirements for funding agencies, they believe the 6-month requirement for reporting is sufficient, and they are limited in what their software and other database systems are capable of processing. However, they also stated that changes to staging and other data elements also limit their ability to address timeliness issues – that resources are currently spent trying to just keep up with changes to variables and there are delays in implementation.

- 5) Data Quality and Completeness Approximately 46% of registries (24 of 52) reported that at least 80% of cases are reported within state guidelines. This increases to 63% if we add 9 registries who reported that 70-80% of cases are reported within state guidelines. However, 15 (28%) registries reported that less than 50% of cases were reported within the timelines required by their state. Most registries use the NAACCR method estimate to evaluate completeness (n=40), but some use other methods promulgated by SEER or other methods. When asked about how often specific edits packages are used, 48% (n=25) cited that they use edits within their internal database management systems "on the fly" (anytime); 50% (n=26) and 23% (n=12) use NAACCR edits anytime and once a year, respectively; 30.8% (n=16) use NPCR-CSS edits anytime and 21% (n=11) use it once a year. Four of 5 registries that cited use of an "In-house mimic of Statistics Canada" edits use it once a year.
- c. Conclusions/Recommendations
  - Recommend focusing effort to improve *timeliness* as real-time reporting is not yet feasible - 76% (41/54) require reports < 6 months of dx (or last contact or first visit), 51% (23/45 US) report that > 75% of cases reported by CoC facilities, and another 15 registries reported that 50-75% reported by CoC facilities. *Opportunity: Leverage Rapid Quality Reporting System (RQRS) @CoC facilities*
  - Varied central registry database management software with varied capabilities - 70% (38/54) are able to process NAACCR modified records or other updates. *Challenge: NAACCR modified records or other updates done with some level of manual processing (11 entirely manual)*
  - 3) Few registries conduct two-tiered reporting (excl. e-path, ECC). *Opportunity: Leverage expertise from these registries.*
  - 4) **Opportunity: Implement registry requirements to improve incidence data from non-hospital electronic sources.** Majority of registries do not receive CAP cancer checklist as part of reports nor do they consistently require key variables beyond name and sex as part of early case notification processes. Some registries are implementing initiatives to enhance electronic reporting from pathology labs and physician offices, and exploring or planning to explore transmissions via HIE.
  - Respondents split (55% No vs 45% Yes) on using incidence data early -24/53 said they use data early, 14/22 use data within 9 mos to evaluate reporting patterns/completeness, 10/18 use data 18-24 mos to generate

incidence rates, and 9/12 use data < 6 mos for ECC and 10/17 for RCA. Barrier: General reluctance to use data early. Challenge: Understanding the limitations of the early data. Opportunity: Learn from registries that use early data - what makes them different in terms of data use, registry processes, data quality?

- 6) Although 46% indicated that 80%-100% of cases met their state timeliness requirement, an overwhelming majority of respondents agreed/strongly agreed that improving timeliness would require changes to current cancer surveillance reporting model (80%), operations (94%), or changes to reporting law (67%). *Opportunity: Most registries are either implementing, evaluating, or considering initiatives to improve timeliness (77%).*
- d) Limitations:
  - 1) Not all registries completed the survey (70%) 46 US, 8 Canadian
  - 2) Survey required more time than expected as some respondents were required to consult with other registry staff members to answer questions.
  - 3) Some items in the survey may have been interpreted differently than what might have been intended.
  - 4) Consensus definitions are needed
  - 5) A respondent could answer in each or only some categories and also choose to provide a text response that makes it very hard to see patterns.
  - 6) Don't know/No plans type responses it is possible that the responder was not responsible for that area of activity/that the answer needed group input. Registries and their agencies may have structured plans that are not visible in the survey results.
  - Lack of community-of-practice concordance on definitions such as "incidence file/year" may be responsible for answers that seem internally contradictory.
- e) Next steps:
  - 1) Investigate the feasibility of changing central registry reporting timeliness standards to reflect better current practices and needs of registries and their customers (focus groups).
  - 2) Assemble a group of interested registries to conduct more detailed analysis of 2015 or 2016 data (special study) to look at data quality at varying points in time, characteristics of cases reported at specific time points, and timeliness or completeness of reporting at specific time points.

#### IV. 12-Month Data

- a. Methods A ratio of 2013 diagnoses reported in the 2014 NAACCR Call-for-Data (12-month data) and 2013 diagnoses reported in the 2015 NAACCR Call-for-Data (23-month data) were generated and evaluated by registry size (large >75,000 cases/year, medium 25,000-75,000 cases/year, and small < 25,000 cases/year) and cancer site. Scatter plots of the % of cases with known stage, race, and surgery status for 12-month and 23-month data and distributions of reporting source were also generated to compare the quality and source of data between the two submissions. Results from an analysis on 12-month data reported to NAACCR was included in the September webinar, presented by Frank Boscoe (NY, 12-Month Data Task Force chair).
- Results Few registries have 95% or more of their cases when 12-month data are submitted, but a little more than half of all registries have at least 80%. Larger registries are more complete relative to small registries with less than 25,000 cases per year, with the average hovering around 80% amongst all registries. The ratio of 12-month data to 23-month data counts vary by cancer site, but breast cancer cases are among the most complete by the 12-month submission (see Figures 4).





Scatter plots show that completeness of the race variable is somewhat consistent between the 12- and 23-month data submissions (points clustered in the upper right quadrant and around the line) (Figure 5a). However, we found that while the percentage of cases with known stage and surgery status remains high between submissions, the percentage actually drops from the 12-month data submission to the 23-month data submission (points below the line) (Figures 5b and 5c). The distribution of cases by type of reporting source show that the declines in these variables are likely due to the addition of cases that are reported from sources that lack these variables (e.g., death certificates, laboratory-only, physician-only, and outpatient radiation or surgery centers) (Figure 6).



Figure 5. Scatter Plots of % (a) Known Race, (b) Known Stage, and (c) Known Surgery Status for 2013 diagnoses reported between 2014 (12-month) and 2015 (23-month) data submissions.

Figure 6. Distribution	of Reporting Source	by 12- and 23-month	n data submissions
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Type of Reporting Source	First 12 months	12-23 months	Overall
Autopsy only	0.0	0.2	0.0
Death certificate only	0.1	9.6	1.7
Hospital inpatient/outpatient or clinic	88.2	71.1	85.3
Laboratory only (hospital or private)	2.2	6.0	2.8
Nursing/convalescent home/hospice	0.0	0.5	0.1
Other hospital outpatient unit or surgery center (2006+)	5.6	0.8	4.8
Physicians office/private medical practitioner (LMD)	1.5	8.2	2.6
Radiation treatment or medical oncology center (2006+)	2.4	3.7	2.6

c. Conclusion – Findings support what registries reported in the survey that not all registries have complete data 12-months; and, the overall data quality is better with 12-month data, which has limited path-, physician-, and DC-only cases with poor quality. *Challenge: Address reporting delays to central registry Opportunity: Evaluate the fitness-for-use of data at 12-months (80% sample) and determine which data may be released earlier.* 

#### V. Special Study

a. Methods

The TF invited nineteen state/regional/provincial registries to submit data for this analysis. These registries previously indicated interest with participating in this phase of the project.

The TF provided each registry with a SAS program to run against their data. The SAS program evaluated cases that were residents of each state and diagnosed in 2013 or 2014. Death certificate only (Type of Reporting Source = 7) cases were excluded. Dates that were used in calculations (date of diagnosis, date of last contact, and treatment dates) were recoded if elements were blank. Blank day was recoded to '15' and blank month was recoded to '7'. All cases were recoded

into SEER site groups for analysis. Each registry returned their output to one TF member. The output included the following percentage measures:

- cases dying within 90 days
- in situ cases
- total cases among top 5 and top 10 sites
- total hematopoietic cases (leukemia, Waldenstrom's, multiple myeloma)
- cases treated with surgery as the first treatment (among top 5 sites that live 90+ days) Participating registries also reported mean and median number of days from diagnosis to surgery for those cases first treated with surgery.

#### b. Results

The TF received data from thirteen registries, all of which were US state or regional registries.

By annual case load, the registries that provided data can be characterized as four small, four medium, and five large. Three registries are in the West region of the US, eight are in the East region, and two in the Midwest region. One of the registries is a SEER registry; one is dually funded by SEER and NPCR; the remainder are NPCR registries. All participating registries are NAACCR gold certified for data quality and completeness. **Table 1** shows that each of the measures is similar across all registries. For the category Percentage of Cases Treated First with Surgery, data from Registry 13 could not be used as the numbers were clear outliers. The results could not be confirmed with this registry prior to writing this report. Across the 13 registries, approximately 55% of total caseload is represented by the top five sites (breast, prostate, lung, melanoma, and colorectal) and 73% of total caseload is represented by a registry's top 10 sites. The top 10 sites varied by registry.

Among cases that survived at least 90 days after diagnosis, a high percentage of breast, melanoma, and colorectal cases are treated by surgery as their first treatment on average. The percentage is much lower for prostate (37.5%) and lung (27.3%), which would be expected. This measure is of significance because all the elements of an incidence case should be available once surgery is complete, including a pathologic stage. For the three cancers that are usually first treated with surgery, the surgery takes place on average within a relatively short period of time from diagnosis – 45 days for breast, 9 days for melanoma, and 18 days for colorectal. When lung cancers are treated first with surgery, the average time from diagnosis to surgery was 35 days.

	Registry 1	Registry 2	Registry 6	Registry 10	Registry 12	Registry 4	Registry 5	Registry 7	Registry 8	Registry 9	Registry 11	Registry 13	Registry 3	AVERAGE
	Negisti y 1	negisti y z	Registry o	Incessory 10	Incensory 12	inegisti y 4	inegistry 5	itegistiy /	negistry o	negistry 5	Incensory 11	Negistry 15	inegistry 5	
Funding source	Dual	NPCR	NPCR	NPCR	NPCR	NPCR	NPCR	SEER	NPCR	NPCR	NPCR	NPCR	NPCR	
Region	West	East	East	Midwest	East	West	East	East	East	East	West	Midwest	East	
Registry size	Large	Large	Large	Large	Large	Medium	Medium	Medium	Medium	Small	Small	Small	Small	
% of cases dying within 90 days														
	4.0	7.9	9.3	9.8	9.3	8.1	7.9	8.2	9.2	7.3	9.1	9.7	9.0	8.37
% in situ (all cases)														
/ In situ (an cases)	14 1	10.4	12 7	86	10.7	10.8	10.0	11.6	10.4	13 5	9.4	11 7	11.0	11 14
	11	10.1		0.0	10.7	10.0	10.0	11.0	10	10.0	5.1		11.0	
% of total cases top 5 sites														
	53.9	52.5	53.4	55.5	56.6	53.3	57.1	54.1	54.1	57.5	52.8	55.1	54.4	54.64
% of total cases top 10 sites														
	71.2	71.1	75.4	73.9	72.5	70.9	74.1	75.5	73.3	75.0	70.4	76.1	74.1	73.34
% of total hematopoietic														
(leukemia, Waldenstrom's, multiple														
mveloma)														
	5.2	6.0	5.3	4.1	5.3	5.2	4.1	5.7	4.7	4.8	4.1	5.1	5.4	5.00
% of cases (by site) treated first														
with surgery (among top 5 sites that														
iive 90+ days)														
Breast	78.7	81.1	82.9	80.3	82.2	83.3	83.6	79.1	86.3	87.6	72.0		87.1	82.01
Prostate	38.0	29.8	40.2	37.3	37.7	32.5	36.3	33.3	44.3	43.9	36.4		40.1	37.49
Lung	18.9	32.1	28.4	26.9	23.7	26.6	25.7	31.2	37.5	27.7	20.2		28.1	27.26
Melanoma	87.5	86.6	88.9	87.4	87.9	94.4	80.2	93.7	94.6	83.2	81.9		96.3	88.54
Colorectal	81.0	82.2	87.3	84.5	85.7	88.2	84.5	84.2	87.4	80.6	76.8		87.1	84.11
Mean number of days (by site)														
between diagnosis and surgery date														
(among top 5 sites that live 90+														
days)														
Burnet	40.0	47.1	46.0	45.0	42.0	42.2	46.0	52.2	42.0	40.7	20.0	42.0	27.0	44.50
Breast	49.8	47.1	46.0	45.8	43.8	42.2	46.8	52.3	42.0	43.7	39.0	43.8	37.0	44.56
Lung	38.8	34.6	34.0	/11 0	35.2	37.6	26.1	35.0	29.0	31.0	37.0	13.6	31.1	35.06
Melanoma	13.2	14.0	11 3	11.3	43	5.7	7.5	7 7	10.2	8.9	12.7	7 1	5 5	9 17
Colorectal	21.2	22.4	19.3	20.9	18.6	15.7	16.5	20.4	19.3	18.7	14.9	14.3	17.2	18.41
Median number of days (by site)														
between diagnosis and surgery date														
(among top 5 sites that live 90+														
days)														
Breast	34	35	33	31	. 30	32	33	36	32	35	22	27	28	31.38
Prostate	66	65	64	57	60	61	64	67	72	62	55	59	68	63.08
Lung	29	20	23	34	25	25	14	22	15	16	25.5	34	22	23.42
Melanoma	0	0	0	0	0	0	0	0	0	0	0	0	0	0.00
Colorectal	/	9	6	-	- <b>/</b>	5	5	5	9	9.5	8.5	5 3	8	6.92

#### Table 1. Percent of cases according to key metrics by Registry.

#### **Discussion/Limitations**

The analysis measures were very similar across all participating registries. Reports to central registries could be considered complete for incidence purposes when they contain patient demographics (name, address, date of birth/age, gender, race, ethnicity), certain tumor-related items (site, laterality, histology, behavior, date of diagnosis, stage). In situ cases, patients who die shortly after diagnosis, and hematopoietic cases would most likely be complete within a very short period of time. Those patients who died (8.4%) will have no more information straggling in. In most situations, in situ cases (11.1%) are treated with surgery alone which is typically completed quickly after initial diagnosis. Hematopoietic cases that are

always staged distant (leukemias, Waldenstrom's, multiple myeloma) represented about 5% of the total caseloads in registries. These three categories together represent nearly 25% of a registry's total caseload.

One limitation of this analysis is small sample size. It would be interesting to include more registry data in the analysis and perhaps attempt to replicate as many parts as possible with the full NAACCR analytic file. Another limitation is the lack of Canadian representation in the sample. Unfortunately, the Canadian registries that initially indicated willingness to participate were unable to do so when the TF issued the call for participants. A further limitation with these data is that the TF had no information on specific registry practices that could affect the analysis, such as whether registries pursue complete treatment information after an initial case report, specific record-consolidation practices, follow-up practices, etc.

Data management and software limitations are potential barriers and create a reluctance by some central registries. In addition, staff and other resource constraints may prohibit the ability to engage in more timely reporting, as cases may require multiple processing steps.

This analysis was a fairly high level and somewhat rudimentary first look at the characteristics of cases submitted to central cancer registries. Further analysis might include stratification by type of reporting source or a more detailed look at the time to initiation of the last treatment on record.

#### VI. Focus Groups

#### a. Methods

Focus groups discussions focused on 3 areas: (1) Early use of registry data; (2) Strategies to improve timeliness; and (3) Two-tiered reporting. An invitation was sent to all US registries that participated in the survey. Eighteen (18) registries signed up for 1 of 3 focus group sessions and a 4<sup>th</sup> make-up session was offered in case participants were unable to attend the original session they signed up for. The TF decided not to include Canadian registries.

Participant rosters, the focus group agenda, and background material for the focus groups, which were distributed to participants ahead of time, are included in <u>Appendix B</u>. Focus groups were co-led by Nan Stroup, Mary Jane King, and Lori Havener. Facilitators used a Question Guide to ensure that key questions were addressed and they had follow-up or probative questions on hand if needed. The Question Guide was also used to document responses. Each focus group took between 1.5 – 2 hours to complete and they were all conducted via Web-Ex.

Notes were reviewed and themes were identified by Nan Stroup and Mary Jane King. Responses were summarized using a mind-mapping<sup>1</sup> technique that helps to organize and highlight major themes.

- b. Results Figures 1-3 show the mind map generated for 2 of the 4 focus groups.
  - 1) Early Use of Registry Data Registries cited a few ways that they used data early including cancer cluster investigations, release to Department of Health as preliminary data for surveillance statistics, submission of 12-month data to NAACCR, and research (e.g., use of path reports for case ascertainment, use of early reports for recruitment into clinical trials and other survey research). One registry stated that they do not use data until after the annual calls for data, with no exceptions. Early use for cancer cluster investigations was limited to a few data items such as primary site, diagnosis date, age at diagnosis, and demographic information.
  - 2) Strategies to Improve Timeliness One thing that was clear by the responses is that registries use multiple strategies to improve timeliness of reporting. Strategies included communications with providers including reports and feedback to hospitals and other reporters; participation in interstate data exchange programs and the CDC early case capture initiative; accepting all records submitted (no rejections which might cause delays) which often include central registries helping reporters address specific vendor issues; and, promoting the use of electronic data submissions (e.g., e-path, WebPlus, PHINMS). Registries also cited reporting delinquent facilities and following up with associated fines, reports to hospital administrators, and even reports to legislative authorities. Most registries require data within 6 months of diagnosis by law, but all expressed interest in getting data sooner. One registry is pursuing a 30-day reporting timeline and another thought that a 4-month submission was feasible for cases that had surgery. Registries also felt that the CoC's RQRS initiative would be a key component for any effort to improve timeliness, but one state was concerned that fewer hospitals were maintaining their CoC status, which would impact central registry reporting timelines. Registries also expressed concern that the lack of experienced CTRs at hospitals as well as central registries is affects our ability to improve timeliness; and, timeliness and quality are impacted when hospitals use contractors.
  - Barriers to Improving Timeliness A number of barriers/challenges were identified by focus group respondents including state reporting laws (providing more time to report), technology (delayed software upgrades, incomplete electronic sources), incomplete treatment data, and registry

<sup>&</sup>lt;sup>1</sup> <u>http://www.mindmapping.com/mind-map.php</u>; <u>https://en.wikipedia.org/wiki/Mind\_map</u>.

processes that may delay completion of case reports. Interestingly, registries also cited staff retention as a barrier, with limited staff, low wages, staff stretched thin having to visit hospitals (contracted to abstract cases) and without streamlined access to electronic health records or remote access. Finally, some registries just don't see the value of improving timeliness.

4) Two-tiered reporting – Overall, there were more barriers identified on this topic as compared to early use and strategies to improve timeliness. However, registries identified several ways that they currently perform "two-tiered reporting" such as the 2-submission schedule for NPCR and SEER, wherein the first submission in Jan/Feb are considered "preliminary" and the final submission in Nov/Dec are considered "complete" and providing "preliminary" data to the Department of Health. Registries expressed concern that a two-tiered reporting system would double their workload and a restructure of registry operations might be necessary to accommodate two submissions per case. All registries stated that more resources would be needed and updates to registry database management systems would be necessary because existing software does not accept "updated" records. One registry noted that they have a two-tiered reporting system wherein they receive data sets with "minimal" data items such as residence, primary site, histology, date of birth, diagnosis date, gender, and race; and, additional sitespecific data items might be requested in the "minimal data set" as well. Some registries thought that a two-tiered reporting system might improve the quality of the data, and registries already receive multiple records from multiple data sources which is likely to help benefit twotiered reporting process. Interestingly, many registries still had questions: (a) what is two-tiered reporting? (b) which standard setters will support two-tiered reporting? (c) what would standards for twotiered reporting look like in terms of variables and edits? and, (d) is there a use-case for two-tiered reporting?

#### VII. Conclusions

Improving the timeliness of cancer surveillance data is an often-debated issue in the NAACCR community. Our research shows that registries are divided into three groups:

- Those that believe that cancer registries are able to meet current timeliness standards and there is no need to change current operations;
- Those that believe that improving timeliness is feasible, and, therefore, we should continue to advance this initiative; and,
- Those that believe that improving timeliness is something that the cancer surveillance community should continue to pursue, but registries lack the financial, human, and technological resources to change the process.

Most registries require that cancer data be reported to central and regional registries within 6 months of diagnosis. Although only about half (46%) of registries reported that surveillance data are submitted according to state reporting requirements, 77% of registries who responded to our survey stated that they are implementing, evaluating, or considering initiatives to improve timeliness, including expansions in electronic reporting and routine feedback to hospitals.

Generating more current cancer incidence rates has been one of the arguments for improving timeliness. However, to use the data early, two-thirds of registries who responded to our survey stated that data had to be at least 90% complete before it can be used. Fortunately, 12-month data has been shown to generate reliable cancer incidence statistics for many cancer sites with appropriate delay-adjustment [1-3].

Our data further suggest that registries may be closer to having complete data than they think. For each registry that participated in our analytic study, the top 10 cancer sites accounted for nearly 75% of all cases for their state/region; and, 88% of melanoma, 84% of colorectal, and 82% of breast cancers were surgically treated and, therefore, complete data including stage could be derived in a timely fashion. Other evidence suggests that 12-month NAACCR data are generally 80% complete and of better quality due to the type of reports that are used to create incidence records. Based on focus group responses, registries will postpone the creation of a cancer case until a full NAACCR abstract is received. This process often delays the creation of a case from other sources that may have been reported earlier (e.g., HL7 e-path records).

Indeed, the ability to process early (and potentially incomplete) data is one of the most often cited barriers to advancing timeliness. Evidence from the survey as well as the focus groups suggests that information systems are not able to process NAACCR Modified Records in an accurate and efficient way, with a majority of registries updating registry data manually. Given this significant gap in consolidation routines, registries are hesitant to create new cancer incidence records based on incomplete case reports that would have to be "updated" or "modified" with subsequent records and are ill-prepared to implement a two-tiered reporting system. Prior studies have found that resubmissions from hospitals to central registries after 15-months have resulted in improved data, but they also found that updates are in fact feasible and could be implemented [4-6].

Although barriers and challenges have been expressed by registries, we found that 36% of survey respondents were in favor of changing reporting timelines for research purposes. In focus groups, we found that registries used data early for rapid case ascertainment studies and clinical trials, the CDC's early case capture project, cancer cluster investigations, and some are used to generate preliminary incidence statistics. Early use of data was also limited to specific demographic and tumor fields and excluded treatment and stage. The CoC's RQRS tool was also recommended by some registries as

a possible resource for real time data, however, the frequent changes to reporting requirements may hinder this effort as hospital registrars struggle to keep up with new and revised coding guidelines, staging variables, and additional data requirements.

#### VIII. Recommendations and Next Steps

- Stabilize cancer data standards so that registries can focus on improving timeliness.
- Improve software tools to enable registries to accept early incidence reports, which may have incomplete data, and to auto-consolidate data to decrease manual review and editing by registrars.
- Develop guidelines of central registry processes to improve their timeliness, providing feedback to hospitals and other reporting facilities, and determining minimum/core data elements for an early incidence report.
- Evaluate how central registries can leverage the RQRS system to enhance reporting.
- Work with central registries to determine feasibility of shortening reporting requirements to less than 6 months (4 months or 2 months), understand resource constraints to process multiple and potentially more frequent reports for each case, and evaluate resources needed to revise statutory reporting requirements.
- Develop an ongoing NAACCR process to monitor the quality and completeness of 12month data reported by central registries in the Call-for-Data, including metrics for which improvements can be measured.

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### APPENDIX A: Central Registry Survey

### Central Registry Survey: Feasibility of Improving Timeliness and Reporting Standards

### Conducted by: NAACCR Standardization and Registry Development (S&RD) Assessment of Central Cancer Registry Timeliness and Reporting Standards (ACCR-TRS) Task Force\*

\*Task Force members: Nan Stroup, Randi Rycroft, Mary Jane King, Winny Roshala, Maria Celaya, Lori Havener. Contributions from S&RD Steering Committee, and Frank Boscoe, Reda Wilson, MaryBeth Culp, and Recinda Sherman from the NAACCR 12-Month Data Task Force.

Over the past several years, NAACCR hosted several sessions focused on the "Registry of the Future". One of the common themes emanating from those sessions is that the registry of the future must be able to produce incidence rates in a more timely manner to meet customers' needs. The Assessment of Central Cancer Registry Timeliness and Reporting Standards (ACCR-TRS) Task Force is focusing on this aspect of the Registry of the Future and seeks your assistance in helping us investigate the feasibility of changing central registry reporting timeliness standards to reflect better current practices and needs of registries and their customers.

Please help us document the current situation in your state, provincial or territorial cancer registry by completing the following survey. The survey should take around 15 minutes to complete based on your answers. Please complete no later than Mary 23, 11:59 pm CT.

The results of this survey will be discussed at the 2016 NAACCR Annual Conference in at a special breakout session.

## A. **REGISTRY PROFILE**

- A.1. Country
  - U.S.

Canada

- A.2. Program Funding (choose all that apply)
  - CDC NPCR

NCI SEER

] State, Provincial, or Territorial Government

Other	(specify	1	) :
Other			

- A.3. Catchment Area
  - Statewide or Provincial
  - Regional (within State/Province)
  - Special Population (may cross State administrative boundaries)
  - Other (specify): \_\_\_\_\_
- A.4. Average size of incidence file per year
  - \_\_\_\_ < 10,000 per year
  - \_\_\_\_ 10,000 19,999 per year
  - \_\_\_\_ 20,000 29,999 per year
  - \_\_\_\_ 30,000 39,999 per year
  - \_\_\_\_ 40,000 49,999 per year
  - 50,000 74,999 per year
  - \_\_\_\_ 75,000 100,000 per year
  - \_\_\_ > 100,000 per year
- A.5. When are facilities required to report incident cases to the central registry?
  - Within 1-2 months of diagnosis/date of last contact/date of first visit
  - Within 4 months of diagnosis/date of last contact/date of first visit
  - Within 6 months of diagnosis/date of last contact/date of first visit
  - Within 12 months of diagnosis/date of last contact/date of first visit
  - Requirements vary by reporting source or type of record (please explain):

Other:

- A.6. Proportion of incident cases reported as 'analytic' cases by CoC-approved facilities  $\Box < 10\%$ 
  - 10% 25%
  - \_\_\_\_25% 50%
  - \_\_\_\_50% 75%
  - \_\_\_\_ > 75%
  - Not Applicable (Canadian registries or no CoC programs)

A.7. What central registry database management system do you use to process incidence records (check all that apply)

SEER*DMS	
Registry Plus	
Commercial Vendor (specify, e.g., RMCDS, Precis, ERS):	
In-House Software Package (specify):	_
Other (specify):	

A.8. Is your central registry database management software capable of processing modified NAACCR records or other updates to existing cases in your database?

[	Yes (go to A.9)
[	No (go to B.1)
[	Don't Know (go to B.1)

A.9. Describe how modified records or updates to existing NAACCR abstracts are processed (e.g., automated updates by software, manual updates by coding staff, etc.).

## **B.** Incidence Reporting

**B.1.** Does your registry currently engage in some sort of two-tiered\* or early case capture reporting system?

Yes (go to question B.2)

No (go to question B.4)

Don't Know (go to question B.4)

\* For the purposes of this survey, two-tiered reporting or early case capture consists of at least two instances of incidence reporting by the same facility on the same patient and tumor to the central registry. The first instance (tier #1) may include a <u>minimum</u> amount of data about the case to create an incidence record (e.g., name, social security number, race, ethnicity, date of birth, primary site, histology, date of diagnosis, stage, etc.). This initial report is then followed by a more complete abstract with additional data to complete the incidence record (e.g., treatment, biomarkers, etc.). The second report (tier #2) might have more complete data and be flagged as a modified NAACCR abstract.

B.2. Please describe your registry's two-tiered reporting system.

B.3. Please check the variables that your registry requires for the initial report (Tier 1):

Name (First, Middle, Last)	Date of diagnosis
Date of birth	Primary Site
Address	Histology
SSN SSN	Grade
Sex Sex	Behavior
Race	Laterality
Ethnicity (Spanish Origin)	Stage

Canadian Provincial/Territorial Patient Identifier

Other (List):

Please rate each of the following:	Strongly	Agree	Disagree	Strongly	Undecided
	Agree			Disagree	
B.4. Although my registry does not currently					
engage in two-tiered reporting, I would be					
interested in learning more about the process and					
how my registry might benefit from it.					
B.5. The completeness of registry data will be					
improved by two-tiered reporting.					
B.6. The quality of registry data will be improved by					
two-tiered reporting.					
B.7. Incidence rates may be released in a more timely					
manner with two-tiered reporting.					
B.8. Data will be available for research in a more timely					
manner with two-tiered reporting.					
B.9. There are significant challenges to implementing					
two-tiered reporting on a state/regional/provincial level.					
B.10. Please comment on any of the items above and desc	ribe the c	hallenges	that your i	registry mig	ht face in
implementing two-tiered reporting.					

B.11. Does your registry receive case notification via the CAP protocol electronic Cancer Checklist from reporting facilities?

] Yes (go to question B.12)

] No, planning to assess (go to question B.123)

No, in development (go to question B.12)

] No, no plans to assess or develop (go to question B.13)

Don't Know (go to question B.13)

B.12. If your registry currently receives or is planning to receive case notification via the CAP protocol electronic Cancer Checklist, please describe what has been done or what is planned.

B.13. Is your registry currently involved with any Health Information Exchanges (HIEs)\*\* to facilitate cancer casefinding and reporting?

Yes, for casefinding and reporting (go to question B.14)

Yes, for casefinding only (go to question B.14)

Yes, for reporting only (go to question B.14)

No, but plan to assess (go to question B.15)

No, no plans to assess or use HIEs (go to question B.15)

Don't Know (go to question B.16)

\*\* For information about HIEs, please visit <a href="https://www.healthit.gov/HIE">https://www.healthit.gov/HIE</a>.

B.14. If your registry is currently involved in HIEs, please describe (go to question B.16).

B.15. Please explain why your registry is NOT currently involved in HIEs (e.g., resources, priorities, no HIE or no functional HIE, etc.).

B.16. Is your registry assessing or implementing any initiatives to obtain direct electronic casefinding feeds (e.g., CDA, e-Path, PHINMS) from reporting facilities?



Yes (go to question B.17) No (go to question C.1)

Don't Know (go to question C.1)

B.17. What types of reporting facilities does your registry obtain direct electronic casefinding feeds and in what format or exchange standard? (check all that apply)

Hospitals (specify, e.g., CDA?): Pathology labs (specify, e.g., e-Path, PHINMS, etc.): Physician Offices/Clinics (specify, e.g., CDA, Meaningful Use): Radiation Oncology or Outpatient Surgical centers (specify, e.g., claims) Other (specify):

#### **Timeliness C**.

C.1. Does your registry use incidence data (all or in part) **before** it is submitted as part of national calls for data (e.g., NAACCR, CDC/NPCR, NCI/SEER, or Statistics Canada)?

Yes (go to question C.2)

No (go to question C.4)

	Number of months after the end of the diagnosis year				gnosis year
C.2. Mark the time frame for each data use	< 6	6-9	9-12	12-18	18-24
(a) Evaluate reporting patterns of facilities					
and assess completeness					
(b) Generate incidence rates					
(c) Early-Case Capture for Rapid Surveillance					
Activities					
(d) Case identification for research studies					
(e.g., rapid case ascertainment)					
(e) Other (specify):					

C.3 What does your registry require before you are able to use the incidence data early?

Please rate each of the following:	Strongly Agree	Agree	Disagree	Strongly Disagree	Undecided
C.4. Registries should change timeliness standards for					
(a) records submitted from reporting facilities.					
(b) incidence data submitted to NPCR/SEER/Statistics Canada.					
(c) incidence data submitted to NAACCR					
(d) incidence data available for research.					
C.5. Improving timeliness will require changing the current model of cancer reporting for surveillance.					
C.6. Improving timeliness will require changes in registry operations.					
C.7. Improving timeliness will require changes to my state/regional/provincial reporting statutes or regulations.					
C.8. Registries should focus on obtaining completed cases within 12 months of diagnosis.					

C.9. Is your registry implementing any new initiatives to improve more timely cancer case identification and reporting?

Γ	
F	

Yes (go to question C.10)

Yes, but in feasibility, planning or development phase (go to question C.10)

No, but assessing options and would like to consider initiatives (go to question D.1)

No, and no plans to do so (go to question C.11)

Don't Know (go to question D.1)

C.10. If your registry is implementing new initiatives to improve more timely cancer case identification and reporting, please describe.

C.11. Please explain why your registry is NOT considering initiatives to improve more timely cancer case identification and reporting.

## D. Data Quality and Completeness

D.1. What percent of cases are reported to your central registry according to the timeline set by your state requirements?

< 10%
10% - 20%
20% – 30%
30% – 40%
40% – 50%
50% - 60%

60% – 70%
70% – 80%
80% – 90%
90% – 100%

D.2. What measurements do you use to estimate yearly completeness of case ascertainment? (Check all that apply)

NAACCR completeness of case ascertainment indicator
Incidence to mortality ratio
Parkin's death certificate notification method
Capture-recapture method
Flow method
SEER Completeness Estimate
Other:

D.3. What edits package do you use periodically to review accuracy of information and how often do you run it? (Note all that apply)

Type of Edits Package	Do Not Use	Any time	Weekly	Monthly	Every 60 Days	Every 90 Days	Once a Year	Other (specify)
(a) Internal database management system edit checks								
(b) NAACCR Edits								
(c) In-house mimic of Statistics Canada edits								
(d) CDC NPCR-CSS data edits								
(e) NCI SEER edits								
(f) Other (specify):								

## E. ADDITIONAL COMMENTS

E. 1. Please share additional comments in this section, particularly if there is information that you would like us to know or that we have omitted in this survey.

If you would like the ACCR TRS Task Force to contact you for participation in future activities related to this topic, please provide the following information:

Registry Name: Contact Name: Contact Email:

Thank you!

## APPENDIX B: Focus Group Materials

## NAACCR ACCR-TRS Task Force Timeliness – Focus Groups

### Agenda

1.	Welcome 1a. Facilitator introductions 1b. Purpose, what lead us here today	(3 minutes)
2.	<ul> <li>Participant Introductions</li> <li>2a. Name, registry, role at registry</li> <li>2b. Who have you brought with you?</li> <li>2c. What are your regulations and requirements regarding timeline/deadlines?</li> </ul>	(10 minutes) greporting
3.	Ground Rules (Nan)	(2 minutes)
4.	<ul> <li>Discussion Topics (20 minutes each, 1-hour total)</li> <li>4a. Among the Participants, Who Uses Data Early? Based on our previous discussions in the task force, "endine before the data are submitted to funding agencies are "ready for submission". Although we believe that the consider "early," alternative definitions could apply. Who uses your data early? What data do they require? When is the early data required?</li> </ul>	(20 minutes) early" might be defined as any es in Nov/Dec – so before they this is what most people
	4b. What Strategies Do You Use to Improve the Timeliness of Your Data?	(20 minutes)
	4c. Discussion of the Concept of Two-Tier Reporting Does your registry do it? What is it? How is it done?	(20 minutes)
5.	Parting Comments and Recommendations from Participa	nts (15 minutes)

\*Total time is 1 hours and 30 minutes, but webinar scheduled for 2 hours to allow for more discussion time if needed.

#### NAACR ACCR-TRS Task Force Timeliness Focus Groups Instructions

**Purpose:** Determine barriers, challenges, and opportunities to improve timeliness of cancer reporting. We plan to do a deep-dive into registry approaches to improve timeliness and document challenges that remain. This is a follow-up to the 2016 timeliness survey distributed to registries prior to the June in-person meeting.

**Structure:** Semi-Structured format, open dialogue with movement through high interest areas as lead by the group. There will be 4 focus group sessions consisting of about 6 participating registries for each session.

- Each registry can have as many representatives on the call as needed to address the questions.
- Focus groups will be held via webinar/conference calls, which are scheduled for 2 hours (1.5 hours for specific agenda topics, plus an extra 30 minutes for additional discussion time if needed)
- Participants are requested to attend 1 focus group session, but we are asking for participants to choose 2 focus group sessions from the list below and designate their first and second choices accordingly.
  - Thursday, May 18, 2017 1:00pm 3:00pm Eastern
  - Wednesday, May 31, 2017 1:00pm 3:00pm Eastern
  - Wednesday, July 12, 2017 1:00pm 3:00pm Eastern
  - Wednesday, August 9, 2017 1:00pm 3:00pm Eastern
  - The Canadian Experience TBD
- Facilitators will do their best to accommodate all participating registries, but in the end, will try to balance each session according to the number of registries per group and the size/type of registry. We also plan to host a separate focus group session for our Canadian partners at a future date TBD.

**Who should participate?** We are open to all participants that responded to the survey last year, but recommend that other registry staff who might be more experienced in how data are used for surveillance and research, how your registry is taking steps to improve timeliness, and your registry's current reporting process and timelines be invited. As noted in the proposed agenda, these are the topics we hope to cover in the focus group sessions.

#### **Role of Participants:**

- *Prepare in advance*. We have provided a tentative agenda and a list of high-level topic areas and questions that we hope to cover on our call. We only ask that participants consider (a) how they would answer the questions and (b) who might need to be invited to ensure that the right people are in the room to answer the questions during the call.
- *Be present!* We are seeking your experience and thoughts around these important timeliness topics and hope to have a good, lively, and thoughtful discussion.
- Contribute to the discussion. Share your thoughts, ideas, and experiences.

- No question is a bad question. Ask away!
- Be considerate of your colleagues' time and contribution. *Leave time for others*.

#### Role of Facilitators (Nan, Mary Jane, Lori):

- Lead webinar
- Initiate questions in each topic
- Ask follow-up or probing questions to expound on specific question or issue
- Track time
- Ensure each participant has time to respond
- Ensure that no single participant dominates the discussion
- Referees discussions
- Documents the discussion

#### NAACCR ACCR-TRS Task Force Focus Group – Question Guide for Facilitators v5/31/2017

Focus Group Session: Wednesday, 5/31/2017, 1pm-3pm Facilitators: Nan Stroup, Mary Jane King, Lori Havener Participants:

No.	Central Registry	Participant Enrolled	Others in attendance (fill in)
1			
2			
3			
4			
5			
6			

Main Question	Follow-Up Questions	Probing Questions
4a. Among the Participants, who uses data early? Based on our previous discussions in the task force, "early" might be defined as anytime before the data are submitted to funding agencies in Nov/Dec – so before they are "ready for submission". Although we believe that this is what most people consider "early," alternative definitions could apply. Facilitator Notes:	<ul> <li>Who uses your data early?</li> <li>What data do they require?</li> <li>When is the early data required?</li> <li>What enables early usefulness of your data?</li> <li>When is it complete enough for "your use"? (Redundant, but the question may surface here rather than in block 1.)</li> <li>What is your measure of completeness/fitness for early use?</li> <li>How do you prep data for early use? Special attention or do your regular processes supply some/all/cohort data early enough?</li> </ul>	<ul> <li>Why is the data wanted early? Research, internal reports, cancer cluster work, early incidence?</li> <li>Can you give an example?</li> <li>Define early for your various uses.</li> <li>Even if your registry does not use early data, is your registry database available to others (e.g. in the Dept of Health) to use?</li> <li>What is the earliest that your data is ready for "your use"?</li> <li>If you use incidence data "early" – why? (surveillance, data quality assessment, etc.)</li> <li>What is your earliest "call for data"?</li> <li>If your jurisdiction has a completion date for an incidence year – what is it? 12 months, 14 months, 23 months?</li> </ul>

Main Question	Follow-Up Questions	Probing Questions
4b. What strategies do you use to improve the timeliness of your data?	<ul> <li>What are the biggest roadblocks to early reporting?</li> <li>What are the core data items for your earliest reporting needs?</li> <li>Do you have a strategy to enable hospitals, doctors, other to report faster with more complete information?</li> </ul>	<ul> <li>If you have timeliness challenges, what strategies have you tried to improve the speed that you receive at least "core data items"</li> <li>Are some types of cancer cases more timely?</li> <li>Can you get information for some cancers earlier/easier than others?</li> <li>What analytic support do you have and how does that help?</li> <li>Do you use ePath? If so, have you found it useful for timeliness? Does it come in before hospital abstracts or afterwards?</li> <li>How much of the core, early data items does your ePath provide? (Synoptic versus narrative reports)</li> </ul>
Facilitator Notes:	Facilitator Notes:	Facilitator Notes:

Main Question	Follow-Up Questions	Probing Questions
4c. Discussion of the concept of two-tier reporting	<ul> <li>Does your registry do it?</li> <li>What is it?</li> <li>How is it done?</li> </ul>	<ul> <li>When does it have enough information to make the cases usable? When is the first tier complete? The second tier?</li> <li>Do your regulations have 2 tiers built into them (e.g. person, case information first; stage and treatment later)?</li> <li>Does this timing coincide with data calls or other planned use of the data?</li> <li>Other than data calls, what is the usefulness of 2-tier?</li> <li>What strategies did you use to achieve 2-tier?</li> <li>What did you do differently for different submitting sources (e.g. physicians versus hospitals versus labs)?</li> <li>Has 2-tier been possible for all cancers, if not which ones and why?</li> <li>If not doing it now, is your registry interested in 2-tier reporting? If so why?</li> </ul>

Facilitator Notes:	Facilitator Notes:	<ul> <li>If 2-tier became the norm, how long would it take for your registry to adopt it? (Canadian registries report at 14 months [no treatment] to the Canadian Cancer Registry, and again at 23 months to NAACCR)</li> <li>Facilitator Notes:</li> </ul>
Facilitator Notes:		