Registry of the Future Open Forum: Real-Time Reporting Update and Discussion

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NAACCR Webinar

Thursday, September 29, 2016

●●●●● Polling Question: Do you think having incidence data earlier is valuable?

A. **Yes, no doubt about it! #duh**

B. **No, not valuable at all #wasteoftime**

C. **Maybe, possibly, #onthefence**

D. **It depends – nothing is ever black/white #gray**

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Assessment of Central Cancer Registry Timeliness & Reporting Standards Task Force (ACCR-TRS)

- Nan Stroup (NJ), Randi Rycroft (CO), Winny Roshala (CA), Mary Jane King (ON, CA), Maria Celeya (NH), Lori Havener (NAACCR)
- Ad hoc: Colleen Sherman (NY), Steve Peace (FL), Serban Negoita (Westat)
- Contributions from 12-Month Data Task Force: Frank Boscoe (NY), Susan Gershman (MA), Reda Wilson (CDC), Mary Beth Culp (CDC), Alana Hudson (WV), and Recinda Sherman (NAACCR)

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ACCR-TRS TF Goals and Objectives

- Real-time reporting identified by NAACCR membership at the Registry of the Future session (Ottawa, ON, CA 2014) and set as a priority activity at Board-Chair Meeting (Miami, FL 2015)
- Goals:
  - Define "real time reporting"
  - Propose strategies to enhance timeliness of cancer reporting
- Objectives:
  - Delineate differences between "real time reporting," "rapid case ascertainment," "early case capture," and "timely reporting"
  - Determine potential costs and benefits to more rapid reporting
  - Determine barriers, challenges, and opportunities to improve timeliness of cancer reporting

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●●●●● ACCR-TRS TF Goals and Objectives

NAACCR

- Strategies:
    1. Online and experiential resources to define key concepts
    2. Survey of registries
    3. Key informant interviews
    4. Collaborate with 12-month data task force

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## ●●●●● Strategy 1: Define Key Concepts

NAACCR

- Real-time:
    - the _actual time_ during which a process or event occurs; or,
    - of or relating to a system in which input data is _processed within milliseconds_ so that it is available virtually immediately as feedback; or,
    - at once or _instantaneously_.
- Timely on the other had is defined as:
    - _occurring at a suitable time_; opportune; well-timed; or,
    - early or soon; or
    - done or occurring at a favorable or _useful time_.

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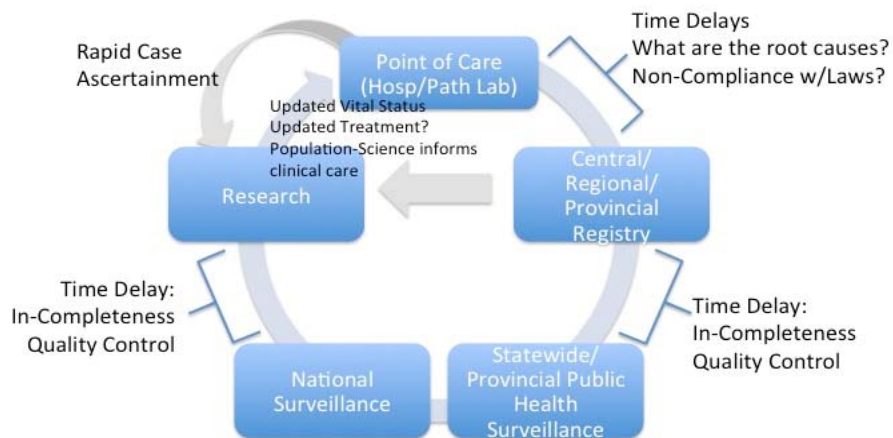
Central Registry Survey: Feasibility of Improving Timeliness and Reporting Standards

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

Strategy 2: Survey NAACCR membership

- Determine barriers, challenges, and opportunities to improve timeliness of cancer reporting
- Online Survey (Thanks, Dustin and Lori!)
- May 9 – 25, 2015
- 4 Sections:
    - A. Registry Profile (Nan)
    - B. Incidence Reporting (Randi)
    - C. Timeliness (Mary Jane)
    - D. Data Quality and Completeness (Winny)
- BONUS!!
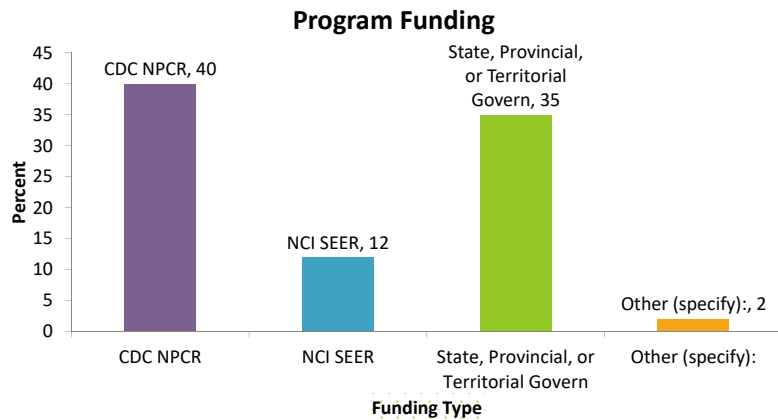   - Quantitative Analysis of 12-month NAACCR data (Frank)
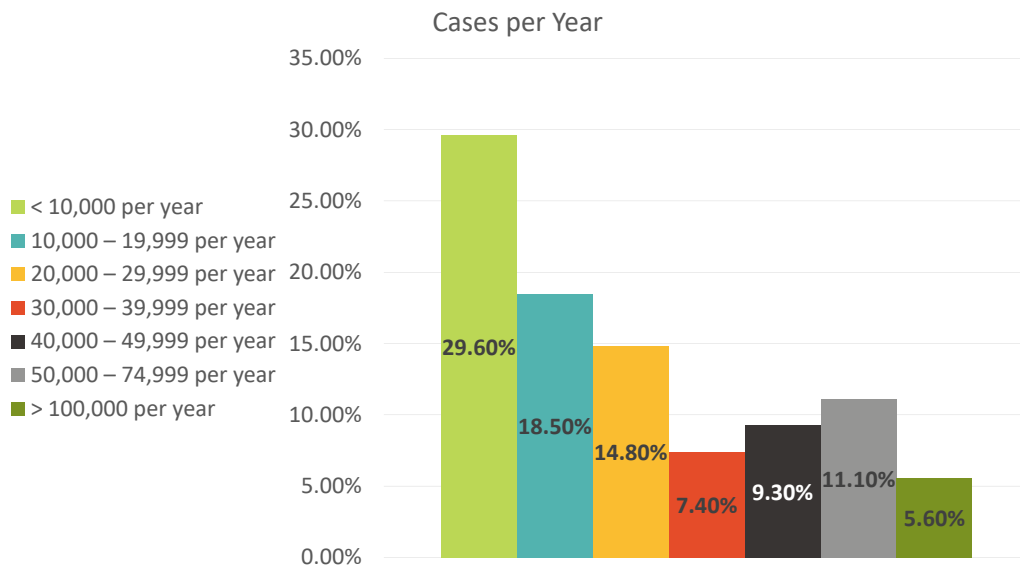
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REGISTRY PROFILE

Nan Stroup

Registry Profile

- 51/73 completed surveys (70%) (6 more completed partial)
- 46 US and 8 Canadian
- 50 state/provincial, 4 regional

Program Funding

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Registry Profile (cont'd)

Cases per Year

Legend:
- < 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
- > 100,000 per year

29.60% 18.50% 14.80% 7.40% 9.30% 11.10% 5.60%

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Registry Profile (cont'd)

- Reporting requirements
  - 36/54 (67%) within 6 months of dx*
  - 5/54 (9%) within 1-2 or 4 months of dx*
  - 10/54 (18.5%) varies by reporting source or "other"
    - Quarterly (CoC), within 15 days, "as soon as possible", reporting conducted through administrative data, law does not specify a time period, "brief" report within 45 days + "definitive" report within 180 days, 7-9 months of dx
- % reported by CoC-approved facilities ("analytic")
  - 53 respondents - 8 N/A Canadian = 45
  - 23/45 (51%) – > 75% CoC
  - 15/45 (33%) – 50%-75% CoC

** Date of diagnosis, date of last contact, or date of first visit

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Registry Profile (cont'd)

Database Management Software Package:
- SEER*DMS n=10
- Registry Plus n=18
- Other (n~29)
  - RMCDS
  - Oncolog
  - Eureka
  - Precis, Precis Central
  - CPDMS
  - FCDS RECAP/IDEA
  - Other state-specific in-house system

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•••••• Registry Profile (cont'd)

Is your central registry database management software capable of processing modified NAACCR records or other updates to existing cases in your database? (N=54)
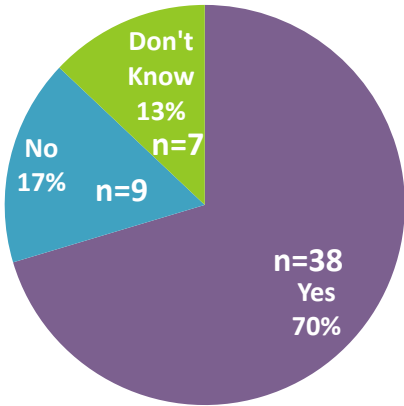
14 Automatic Updates + Manual Updates
 6 Automatic Updates
11 Manual Updates
 5 Unknown, not used, not required, will implement in future
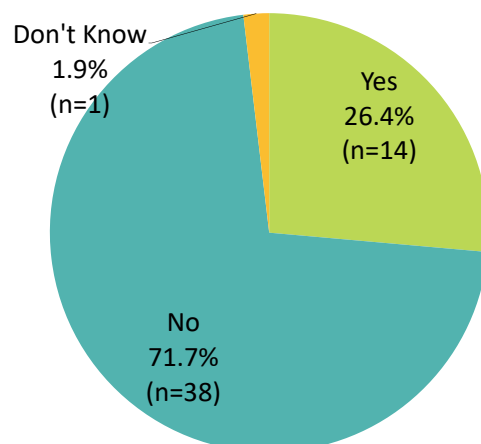
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INCIDENCE REPORTING

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Randi Rycroft

Polling Question: Which element do you currently prioritize first when collecting registry data?

A. Quality #qc_rocks!

B. Timeliness #fasterthebetter

C. Completeness #101%woprostate

D. Whatever we have time to do #overworked

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Current 2-Tiered Reporting

Don't Know
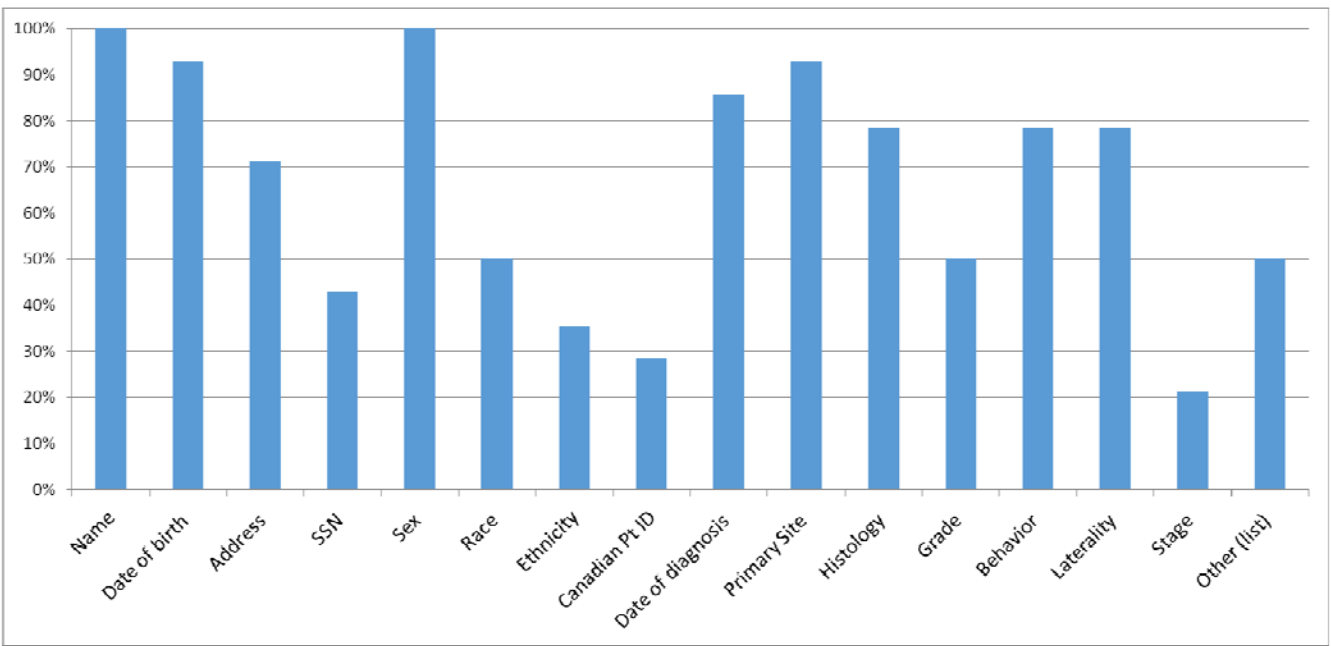1.9%
(n=1)

Yes
26.4%
(n=14)

No
71.7%
(n=38)

Five registries described their 2-tiered system as pathology report followed by hospital report.

Two states mentioned CDC ECC project.
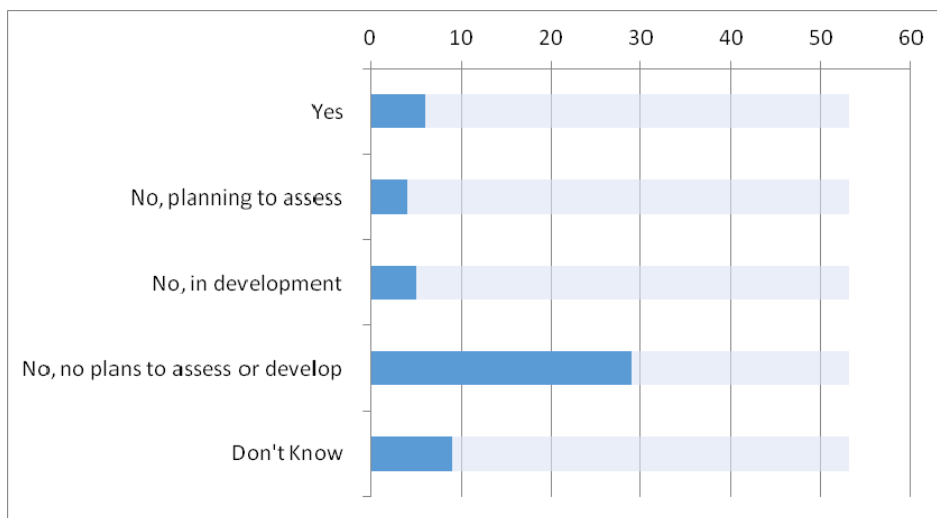
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Variables required for "Tier 1" report (n=14)

CAP electronic checklist (n=53)

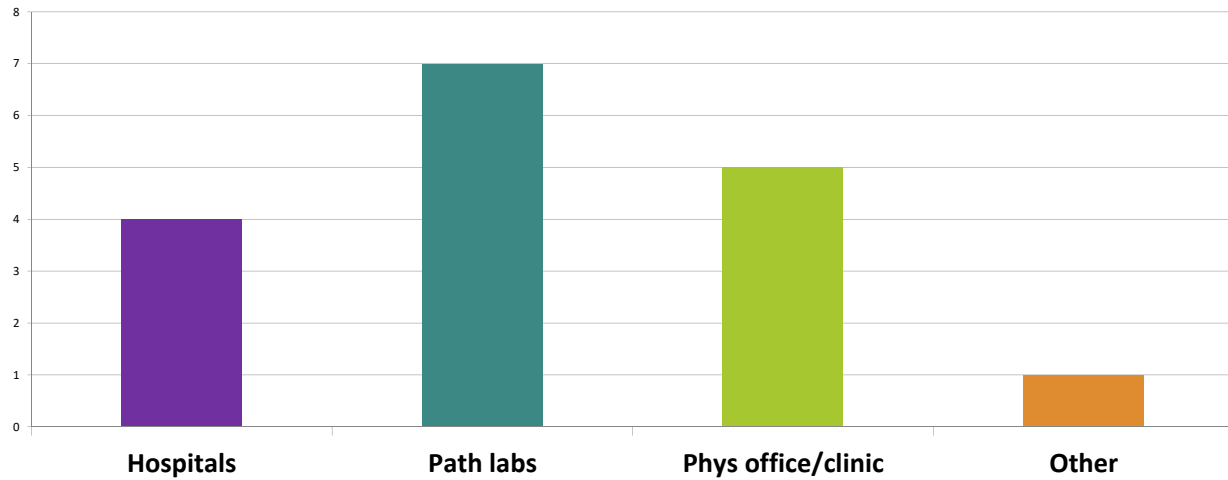Question: Does your registry receive case notification via the CAP protocol electronic Cancer Checklist from reporting facilities?

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Initiatives to obtain e-casefinding feeds from reporting facilities (n=12)

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Participation with HIE (n=38)
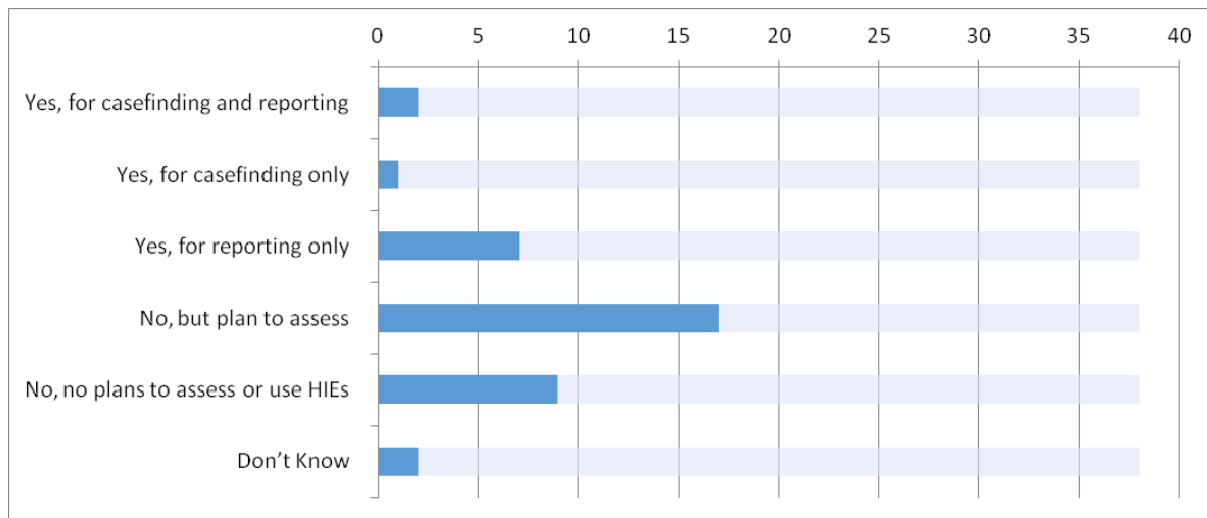
Question: Is your registry currently involved with any Health Information Exchanges (HIEs) to facilitate cancer casefinding and reporting?

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TIMELINESS

Mary Jane King

Polling Question: Which type of early fitness for use is important?

A. Research and other special projects #cancerepi

B. Annual incidence #surveillance

C. Community cancer concerns #cancercluster?

D. Do not use #dangerwillrobinson!

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TIMELINESS

53 out of 57 respondents replied.

There is significant use of data early on.
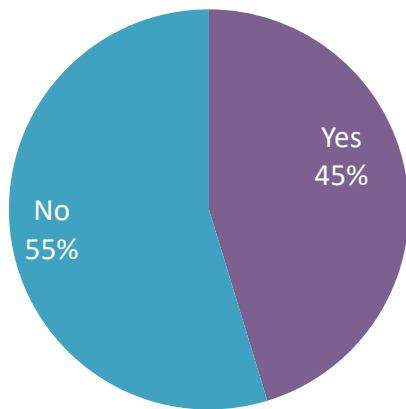
Over half said incidence data was NOT used before the current annual data calls.

Question: 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)?

Value	Percent	Count
Yes	45.3%	24
No	54.7%	29
	Total	53

25

First Follow-up Question for Yes Answers: "Mark the time frame for each data use type below (Number of months after the end of the diagnosis year)"

	<6		6-9		9-12		12-18		18-24		Totals
Evaluate reporting patterns of facilities and assess completeness	27.3%	6	36.4%	8	9.1%	2	22.7%	5	4.5%	1	22
Generate incidence rates	11.1%	2	0%	0	11.1%	2	22.2%	4	55.6%	10	18
Early-Case Capture for Rapid Surveillance Activities	75%	9	8.3%	1	0%	0	8.3%	1	8.3%	1	12
Case identification for research studies, e.g. rapid case ascertainment	58.8%	10	17.6%	3	5.9%	1	5.9%	1	11.8%	2	17

OTHER	Count = 7 (one each) Response
	Following the state health department's Cancer Inquiry Protocol, our CCR can request reporting facilities to report specific data elements for patients w/ specific types of cancer residing in specific areas.
	For some special projects, as soon as a case is received as a rapid report, it is passed to the researcher for use. Other projects require a definitive record and we check monthly and quarterly.
	N/A
	Note for above: Only used usually for research linkage studies
	To identify the cases that should be reported from each facility: Lists of cases identified by the central registry are generated and forwarded to the hospital registrars. We identify the cases we expect to be reported BEFORE the hospital does their casefinding (or concurrently with them) rather than perform an audit AFTER they have reported their abstracts to the central registry.
	We are not conducting the research; we are making the data available to external researchers.
	We do not do early-case capture for surveillance activities nor for research studies.

Four "set questions" and an "Other" category for this question.

Second Follow-up Answer for Yes Answers: "What does your registry require before you are able to use the incidence data early?"

Responses from 21 of the 24 positive responders

Several common themes:

Completeness: ≥90% or "complete"   14 respondents

Stated set of complete variables   4 respondents

Fit per the project requirements (research/studies) - at least 5, maybe more

Some responses indicated that data is not shared until complete

In some instances this response was qualified by "except", e.g. for localized planning purpose; linkage studies

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Registries should change timeliness standards for . . . . .

Percent | Number	Strongly Agree		Agree		Disagree		Strongly Disagree		Undecided		Total
1. . . records submitted from reporting facilities.	7.8%	4	25.5%	13	25.5%	13	7.8%	4	33.3%	17	51
2. . . incidence data submitted to NPCR/SEER/Statistics Canada.	7.8%	4	17.6%	9	27.5%	14	9.8%	5	37.3%	19	51
3. . . incidence data submitted to NAACCR	7.8%	4	13.7%	7	29.4%	15	9.8%	5	39.2%	20	51
4. . . incidence data available for research.	18%	9	18%	9	20%	10	6%	3	38%	19	50

1. A three-way split between strongly agree/agree (17), disagree/strongly (17), and undecided (17)
2. 19 are undecided, 19 disagree/strongly disagree, and 13 strongly agree/agree
3. 20 are undecided, 20 disagree/strongly disagree, and 11 strongly agree/agree
4. 19 are undecided, 18 strongly agree/agree and 13 disagree/strongly disagree

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Please rate each of the following. . .

NAACCR

	Strongly Agree		Agree		Disagree		Strongly Disagree		Undecided		Total
Improving timeliness will require changing the current model of cancer reporting for surveillance.	38%	19	42%	21	6%	3	2%	1	12%	6	50
Improving timeliness will require changes in registry operations.	56%	28	38%	19	0%	0	0%	0	6%	3	50
Improving timeliness will require changes to my state/regional/provincial reporting statutes or regulations.	39.2%	20	27.5%	14	17.6%	9	2%	1	13.7%	7	51
Registries should focus on obtaining completed cases within 12 months of diagnosis.	24%	12	30%	15	18%	9	0%	0	28%	14	50

Number of strongly agree/agree responses are higher for this question

Fewer "undecided" responses

Registry Operations (2nd) seen as requiring the most change (47 of 50, 94%)

Strongly agree/agree responses are greater for the first three questions

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

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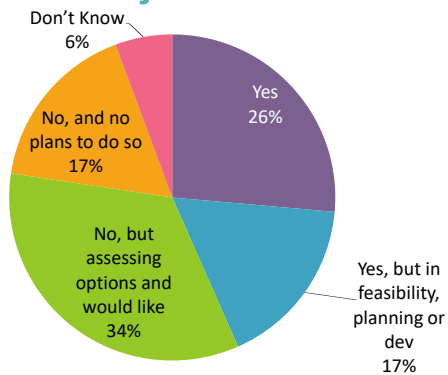
Value	Percent	Count
Yes	26.4%	14
Yes, but in feasibility, planning or development phase	17.0%	9
No, but assessing options and would like to consider initiatives	34.0%	18
No, and no plans to do so	17.0%	9
Don't Know	5.7%	3
	Total	53

Almost half were positive for present or planned implementation (first and second answers = 23 of 53, 43.4%).

The highest single response was No - but assessing/considering (18, 34%)

Nine respondents (17%) had no plans to improve and 3 respondents replied "don't know"

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NAACCR

Follow-up Question for Yes Answers: **"If your registry is implementing new initiatives to improve more timely cancer case identification and reporting, please describe"**

For this question, Yes answers combined Yes, current and Yes, planned only. 21 of 23 responded. Answers were free text.

Developing work-around macros for improving RegistryPlus' ability to move records through Patient Pending and Tumor Pending, linking with Hospital discharge data to identify cases that would have only been identified as DCOs

Extending requirement for hospital reporters to employ HIE SFTP to report securely. (Numbers 17 and 18, above: The meaning is not clear. Change to what? Change from what? Absent this information, no opinion can be rendered.

Flagging cancer reports electronically from source lab systems (8) HL7 to registry. need to implement Oncolog interface manager.

Getting staff to facilities in a more timely fashion

Implementation of more e-path reporting facilities. Awaiting Meaningful Use to more forward.

Implementing additional electronic path reporting in hospital labs; implementing a timeliness feedback mechanism to hospitals.

More follow-back with reporting facilities

One of the Registry's goal is to complete the 24 month data by midyear (july 1, 2016). Last year we reached 70% completion by midyear (2013 call for data) and need to work further to reach at least 90% completeness. The objective is for our Registry to work on 12 month data only

Pathology reports are used to create a patient/tumor in Eureka to allow researchers to use the data sooner. Lots of challenges with this approach.

Patient-centric reporting allowing creation of new cases on limited set of variables.

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NAACCR

Requesting MRDIs and Pathology reports at 13-15 months.

Survey physicians regularly to determine which path labs they use. Contact identified labs to establish regular submission of reportable cases. Regular review of missing accession numbers, deleted cases, non-reportable cases to locate potentially missed cases.

This is specific to funded initiatives and is limited in scope (i.e., early pediatric case capture; pharmaco-surveillance studies - osteo, MTC)

We already report back to hospitals on their timeliness and completeness each month, but we are redesigning the reports using data visualization and we will be incorporating quality measures in the reports. Internally, we are redesigning our completeness and timeliness tracking tools to be more visual, flexible, and interactive.

We are implementing ePath this year which will increase case ascertainment opportunities.

We are involved in a provincial Clinical Information System (multimillion dollar initiative) but this will take many years - it will greatly enhance our workflow both quality and efficiency

We assess reporting from hospitals to see if reports are coming in on a regular basis. We would like to send them data quality reports, which include information on timeliness. We have a Close Out process to assure all data are submitted and follow-up with facilities when numbers are not in sync or appear low.

We implemented a certification process for hospitals to get them to comply with current standards.

early case capture (1 month) of: 1/ pediatric cases ...then... 2/ adult cases

in process.

in the final stage of improving more automated data validation, primary rules and consolidation. It requieres time to have a detailed analyses and testing of the results

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Follow-up Question for No Answers: **"Please explain why your registry is NOT considering initiatives to improve more timely cancer case identification and reporting"**

This question was for No, and no plans respondents. All 9 respondents answered

Given the duration of first course therapy, a six month delay seems reasonable.

No additional resources are available from federal source (NPCR) and decreasing resources from state.

The main driver for timeliness is out-of-state reporting. We are unable to influence how quickly other states report data to us. Also, the quarterly quality indicator reporting to in-state hospitals has been effective as a process improvement measure.

The rest of the system continues to work against us. We can't at the national level get edit sets and other changes to the NAACCR layout and implementation guidelines out on time. This year is a prime example as it is May 2016 and reporting facilities can't report 2016 data as the edits are not ready due to all the changes experienced for 2016. 2017 is going to be the same or worse with AJCC 8th changes which have not even been released to date. These are the larger problems we need to address first before ever attempting to collect more timely data.

We already have the majority of incidence cases identified within 1-4 weeks for histologically confirmed path cases and 4-8 weeks for cases identified using clinical sources (e.g., disease indices, radiation files, oncology files. We cannot move our timeline any closer given the current availability and access to casefinding sources and our staff resources.

We already meet the timeliness requirements set by our funding agency (90% complete - 12 months, 95% complete - 24 months) and we have no additional staff or resources that could be utilized to make improvements.

We currently meet the highest national standards of data completeness and quality

We're generally very timely -- more so when we don't have a backlog of paper and electronic path reports to abstract (which we currently have). Other than that, we ARE moving to a more up-to-date registry system (SEER*DMS). This will require many changes in our manual procedures.

software issues complicate this. There is a shortage of CTR and trained cancer registry staff.
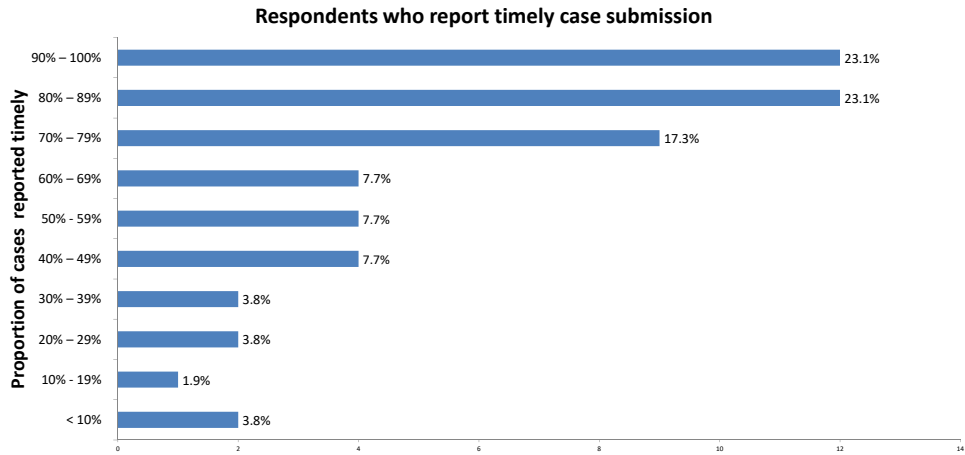

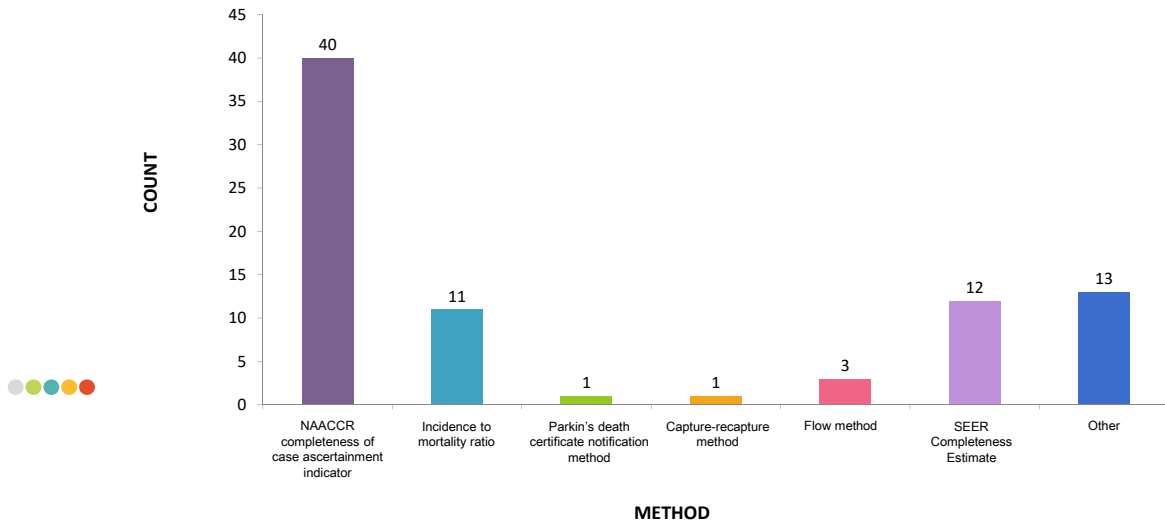# DATA QUALITY & COMPLETENESS

Winny Roshala

What percentage of cases are reported to your central registry according to the timeline set by your state requirements? (n=52)

Respondents who report timely case submission

Proportion of cases reported timely:
- 90% – 100%: 23.1%
- 80% – 89%: 23.1%
- 70% – 79%: 17.3%
- 60% – 69%: 7.7%
- 50% - 59%: 7.7%
- 40% – 49%: 7.7%
- 30% – 39%: 3.8%
- 20% – 29%: 3.8%
- 10% - 19%: 1.9%
- < 10%: 3.8%

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What measurements do you use to estimate yearly completeness of case ascertainment?

COUNT / METHOD
- NAACCR completeness of case ascertainment indicator: 40
- Incidence to mortality ratio: 11
- Parkin's death certificate notification method: 1
- Capture-recapture method: 1
- Flow method: 3
- SEER Completeness Estimate: 12
- Other: 13

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What edits package do you use periodically to review accuracy of information and how often do you run it?

	Do Not Use	Anytime	Weekly	Monthly	Every 60 Days	Every 90 Days	Once a Year
Internal database management system edit checks	14 26.9%	25 48.1%	2 3.8%	4 7.7%	0 0.0%	3 5.8%	4 7.7%
NAACCR Edits	2 3.8%	26 50.0%	1 1.9%	4 7.7%	0 0.0%	7 13.5%	12 23.1%
In-house mimic of Statistics Canada edits	47 90.4%	0 0.0%	0 0.0%	1 1.9%	0 0.0%	0 0.0%	4 7.7%
CDC NPCR-CSS Data edits	12 23.1%	16 30.8%	1 1.9%	5 9.6%	1 1.9%	6 11.5%	11 21.2%
NCI SEER edits	31 59.6%	11 21.2%	1 1.9%	3 5.8%	0 0.0%	1 1.9%	5 9.6%

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12-Month Data Analysis

Frank Boscoe

Percentage of cases with known stage

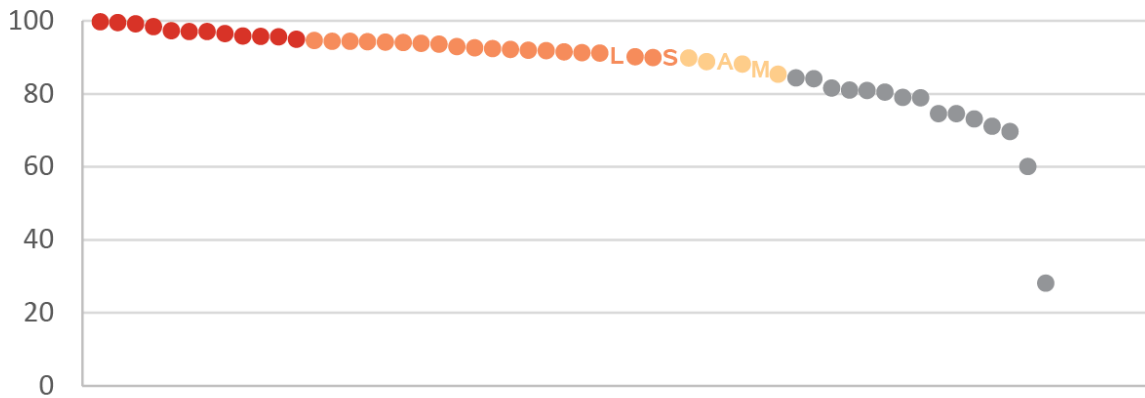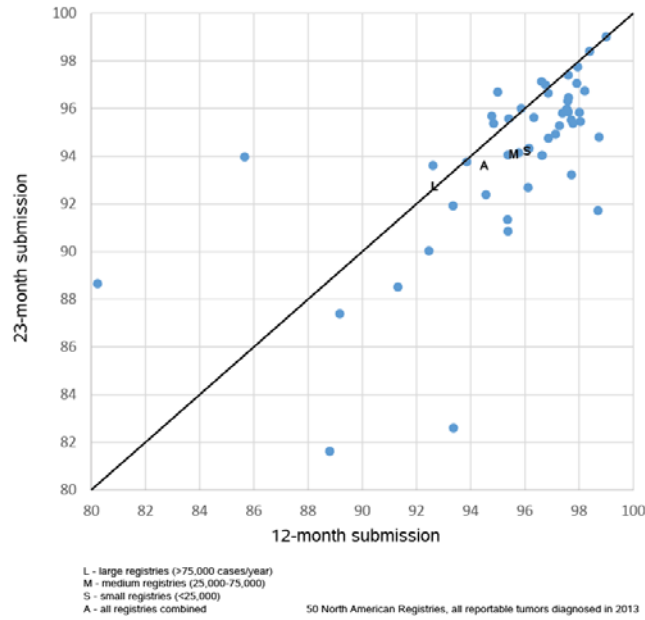Percentage of cases with known race
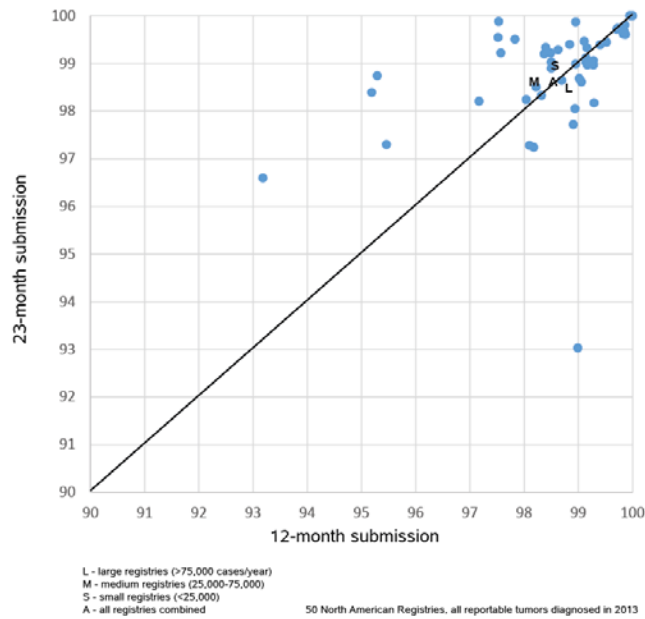
Percentage of cases with known surgery status

L - large registries (>75,000 cases/year)
M - medium registries (25,000-75,000)
S - small registries (<25,000)
A - all registries combined

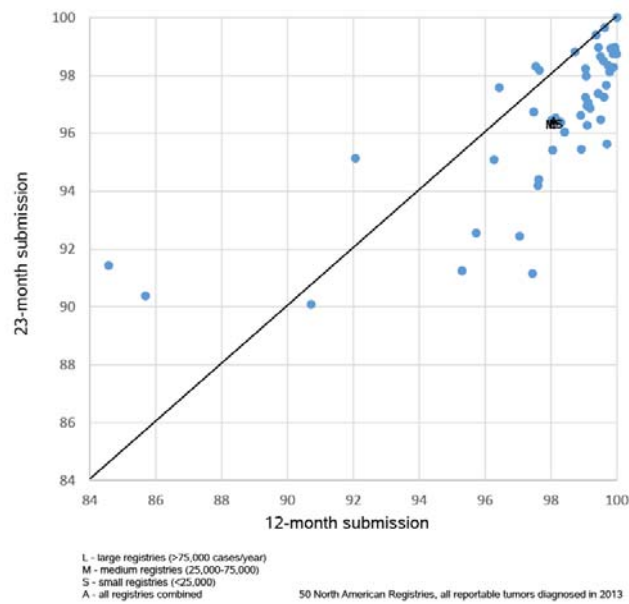50 North American Registries, all reportable tumors diagnosed in 2013

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

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Conclusion

Nan Stroup

Conclusions

- 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)*

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Conclusions: Incidence Reporting

- Few registries conduct two-tiered reporting (excl. e-path, ECC)
  Opportunity: Leverage expertise from these registries
- 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
  Opportunity: Implement registry requirements to improve incidence data from non-hospital electronic sources

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Conclusions: Timeliness

- 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
  - 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?

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Conclusions: Timeliness

Timeliness should be changed for reporting to:
(50-51 Respondents)

■ Strongly Agree/Agree   ■ Strongly Disagree/Disagree   ■ Undecided
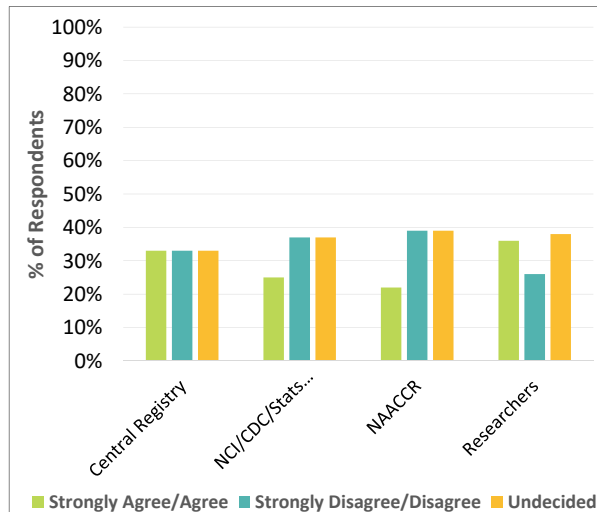
- Overwhelming majority of respondents agreed/strongly agreed that improving timeliness would require changes to current cancer surveillance reporting model (80%), operations (94%), or changes to reporting law (67%)

Opportunity: Most registries are either implementing, evaluating, or considering initiatives to improve timeliness (77%)

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Conclusions: Data Quality and Completeness

- The majority of respondents indicated that they could run their edits package anytime to ensure data quality
- 46% indicated that 80%-100% of cases met their state timeliness requirement
- Consistent with 12-month NAACCR data that not all registries have complete data at 12-months
- Overall data quality better with 12-month data (minimal 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 and determine which data may be released earlier

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Limitations

- Not all registries completed the survey (70%) – 46 US, 8 Canadian
- Survey required more time than expected as some respondents were required to consult with other registry staff members to answer questions
- Some items in the survey may have been interpreted differently than what might have been intended
  - Consensus definitions are needed
  - 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.
  - 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.

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Polling Question: Which element would you now prioritize first when collecting registry data given what we have learned?

A. **Quality**

B. **Timeliness**

C. **Completeness**

D. **Whatever we have time to do**

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Next Steps

- Investigate the feasibility of changing central registry reporting timeliness standards to reflect better current practices and needs of registries and their customers
- Assemble a group of interested registries to conduct more detailed analysis of 2015 or 2016 data (special study)
  - Data quality at varying points in time
  - Characteristics of cases reported at specific time points
  - Timeliness or completeness of reporting at specific time points

Polling Question: Would you be willing to participate in a special project to analyze registry data?

A. Yes #countmein!

B. No #overworked

C. Maybe #asktheboss

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THANK YOU!! - Questions?

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Interested in working with the Assessment of Central Cancer Registry Timeliness & Reporting Standards Task Force in the next phase of this project?

- Contact us!

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