Summary Report

NAACCR Central Registry Readiness for

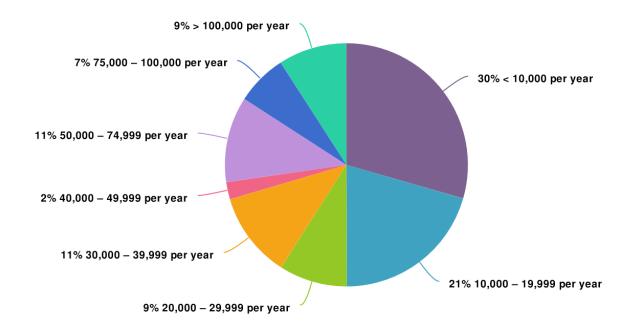2018 Data Changes Implementation Survey – Part II

In an ongoing effort to assess how prepared and ready central registries are to accept and process 2018 data, the NAACCR Standardization and Registry Development Steering Committee (S&RD SC) developed a series of online surveys. The initial survey was distributed in March of 2019, with 39 responses from U.S. central registries and 5 responses from Canadian registries. The results of the initial survey was shared with the NAACCR membership.

The second survey was distributed in July of 2019. A total of 42 survey responses were received, with 38 responses from U.S. registries and 4 responses from Canadian registries.

Frank Boscoe, who conducted the analysis of the initial survey responses, also conducted the analysis for the second survey responses.

Here are the highlights of the second survey results:

Annual Case Volume:

Pie chart showing Annual Case Volume:
- 9% > 100,000 per year
- 7% 75,000 – 100,000 per year
- 11% 50,000 – 74,999 per year
- 2% 40,000 – 49,999 per year
- 11% 30,000 – 39,999 per year
- 9% 20,000 – 29,999 per year
- 21% 10,000 – 19,999 per year
- 30% < 10,000 per year

Are you able to process 2018 cases right now?

	Yes	No	Don't know/ didn't answer
SEER*DMS	8	0	2
Registry Plus	0	12	3
Rocky Mountain	2	7	0
In-house	2	2	3
Other	0	2	1
TOTAL	12 (27%)	23 (52%)	9 (20%)

Spring 2019

	Yes	No	Don't know/ didn't answer
SEER*DMS	9	0	0
Registry Plus	7	3	3
Rocky Mountain	8	3	1
In-house	2	2	1
Other	1	2	0
TOTAL	27 (64%)	10 (24%)	5 (12%)

Summer 2019

Have you received 2018 cases from hospitals?

	Yes	No	Don't know/ didn't answer
SEER*DMS	9	0	0
Registry Plus	9	3	1
Rocky Mountain	8	4	0
In-house	3	1	1
Other	1	1	1
TOTAL	30 (71%)	9 (21%)	3 (7%)

How many 2018 cases have you processed so far?
(as a percentage of expected cases)

Has your central registry finalized the v18 Edits Metafile
for distribution to reporting facility software vendors?

	Yes	No	Don't know/ didn't answer
SEER*DMS	8	1	1
Registry Plus	7	8	0
Rocky Mountain	2	6	1
In-house	3	4	0
Other	0	3	0
TOTAL	15 (34%)	22 (50%)	2 (5%)

Spring 2019

	Yes	No	Don't know/ didn't answer
SEER*DMS	8	1	0
Registry Plus	10	3	0
Rocky Mountain	8	2	2
In-house	3	2	0
Other	0	3	0
TOTAL	29 (69%)	11 (26%)	2 (5%)

Summer 2019

For the 11 registries answering no, when do you anticipate distributing the v18 Edits Metafile for 2018 cases?
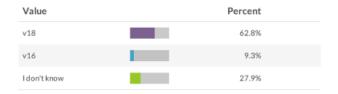
- Not applicable to our registry (3)
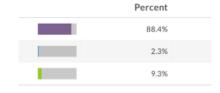- Soon (2)
- Not soon (1)
- Don't know (5)

There continues to be no obvious relationship between 2018 case status and

- Registry case volume

- Percentage of cases from COC-approved facilities

- Where the registry is housed (health department, university, etc.)

In which version will your registry be able to submit their NAACCR Call for Data for 2017 cases?

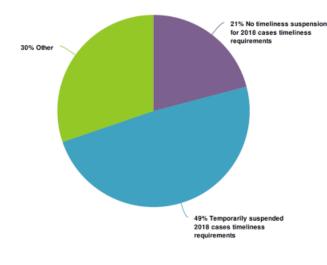| Value		Percent
v18		62.8%
v16		9.3%
I don't know		27.9%

Spring 2019

	Percent
	88.4%
	2.3%
	9.3%

Summer 2019

Has your registry officially suspended reporting timeliness requirements?

21% No timeliness suspension for 2018 cases timeliness requirements

30% Other

49% Temporarily suspended 2018 cases timeliness requirements

"Other" includes:
- Unofficially or informally suspended
- Not applicable
- Legally prohibited from suspending
- Suspension is pending
- Suspension under consideration
- Reporting deadline has been extended
- Suspended enforcement of requirements, not requirements
- Temporary suspension, already lifted
- Suspension has already been lifted

Is your software capable of accepting NAACCR XML from reporting facilities?

	Yes	No	Don't know/ didn't answer
SEER*DMS	8	1	0
Registry Plus	1	6	6
Rocky Mountain	8	0	4
In-house	2	2	1
Other	0	3	0
TOTAL	19 (45%)	12 (29%)	11 (26%)

- Of those who said yes, 15 said they could also process XML, 3 did not know, and 1 said they could not.

In summary, central registries have made progress in their ability to accept and process 2018 cases since the initial survey was conducted. Where feasible, responses from the Spring survey were compared to the Summer survey to monitor improvement.

In the Summer survey, 64% of respondents indicated that they were able to process 2018 cases, 24% indicated they could not process 2018 cases and 12% did not know or did not answer. The responses are broken down by central registry data management systems.

When asked if central registries had received 2018 cases from hospitals, 71% indicated "Yes," 21% indicated "No" and 7% did not know or did not answer. This question was new for the Summer survey, hence there was no comparison to the earlier Spring survey. A significant increase was noted in the percentage of expected 2018 cases processed between the Spring and Summer survey responses.

When asked if the central registry had finalized the v18 Edits Metafile for distribution to reporting facility software vendors, there was dramatic improvement in the responses from the Spring survey. In the Summer survey, 69% indicated "Yes," compared to only 34% in the Spring survey. Of those who indicated "No" in the Summer survey (26%), this was an improvement from the 50% who responded "No" in the Spring survey. Unfortunately, the number of respondents indicating "Don't know, didn't answer, the response remained the same at 5%. Of note, these 2 central registries use the same data management system.   For those central registries that responded they had not finalized the v18 Edits

Metafile, when asked when they anticipate distributing the v18 Edits Metafile, 2 indicated "Soon," 1 indicated "Not Soon," and 5 indicated "Don't know."

There continues to be no apparent relationship between 2018 case status and registry case volume, percentage of cases from Commission on Cancer accredited facilities or where the central registry is housed.

When asked in which version will your central registry by able to submit their NAACCR Call for Data for 2017 cases, 88% indicated v18 in the Summer survey, an increase from 63% in the Spring survey. The "I don't know" responses went from 28% in the Spring, to 9% in the Summer. In addition, those who indicated they would submit their Call for Data 2017 cases in v16 went from 9% in Spring to 2% in the Summer. These results further support that registries are moving toward and making progress in the transition to v18.

Regarding suspension of Timeliness requirements, most central registries implemented some form of temporary requirement suspension, while 21% of respondents indicated "No timeliness requirement suspension for 2018 cases."

The last survey question focused on central registry software capability of accepting NAACCR XML from reporting facilities. The results indicate 45% responding "Yes," 29% indicating "No," and 26% indicating "Don't know, didn't answer." Of those who indicated "Yes," 15 responders indicated they could also process XML, 3 did not know and 1 indicated they could not.

In conclusion, although significant improvements have been made toward accepting and processing 2018 cases, the percentage of "Don't know/didn't answer" responses is concerning. More efforts may be needed to reach out to these central registries to identify the issues and barriers preventing them from moving forward to process 2018 cases.