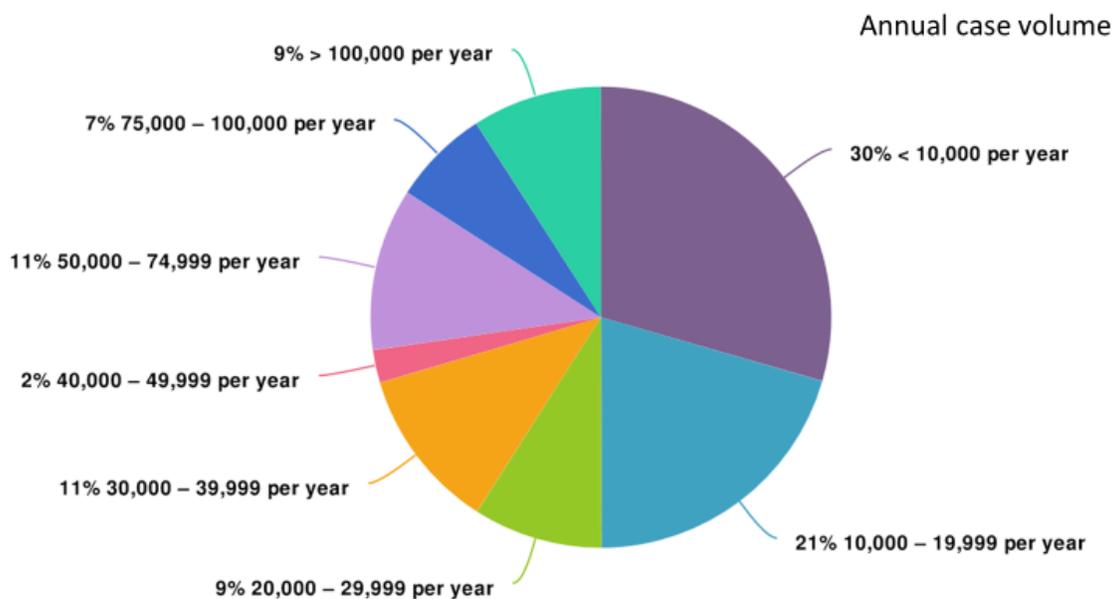


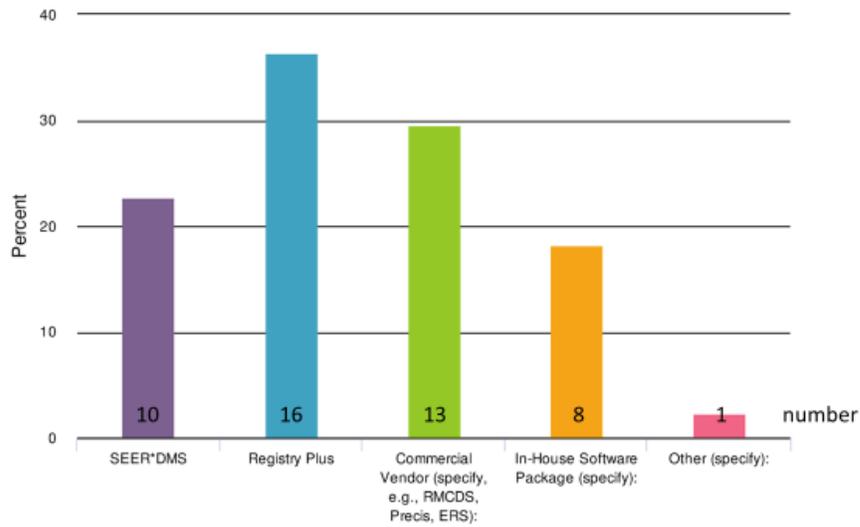
Summary Report NAACCR Central Registry Readiness for 2018 Data Changes Implementation Survey

In an 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 brief online survey. The **survey was distributed on Wednesday, March 6, 2019**, to Registry Directors of NAACCR member organizations, and consisted of 22 questions, including registry profile information and central registry readiness for accepting and processing 2018 cases. A total of 44 surveys were completed and submitted by the given deadline, with 39 responses from US central registries and 5 responses from Canadian registries. This is approximately a 2/3 response rate.

Frank Boscoe conducted an analysis of the survey responses and provided the following results:



What central registry database management system do you use to process incidence records?



Note: Respondents could check more than one. Subsequent slides resolve each registry to a single predominant DMS.

Are you able to receive 2018 cases right now?

| | Yes | No | Don't know/ didn't answer |
|----------------|-------------|-------------|------------------------------|
| SEER*DMS | 9 | 0 | 1 |
| Registry Plus | 2 | 13 | 0 |
| Rocky Mountain | 4 | 5 | 0 |
| In-house | 5 | 2 | 0 |
| Other | 0 | 3 | 1 |
| TOTAL | 20 (45%) | 23 (52%) | 1 (2%) |

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%) |

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

| 2018 cases processed | Number of registries |
|----------------------|----------------------|
| 0% | 24 |
| 0.05-5% | 13 |
| 5-12% | 5 |
| 59% | 1 |
| 70% | 1 |

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%) |

For the 22 registries answering no, when do you anticipate distributing the v18 Edits Metafile for 2018 cases?

- Not applicable to our registry (8)
- When the NAACCR v18 metafile is released (5)
- March (1)
- April (1)
- May (2)
- Don't know (1)
- As soon as we can test it (1)
- Tomorrow (1)
- Yes (1)
- No (1)

There was 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.)

Has your registry staff received adequate training and education to process 2018 cases?

| | Yes | No | Don't know/ didn't answer |
|----------------|-----|----|------------------------------|
| SEER*DMS | 3 | 3 | 4 |
| Registry Plus | 6 | 5 | 4 |
| Rocky Mountain | 4 | 3 | 2 |
| In-house | 2 | 4 | 1 |
| Other | 1 | 2 | 0 |

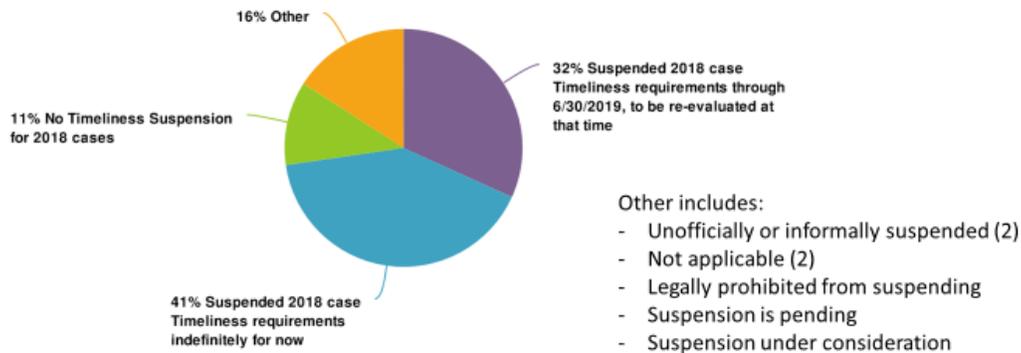
For those who answered no, what are the issues?

- Impossible to assess training needs until 2018 cases processing begins
- Posted webinars are outdated
- Solid tumor rules in particular are questionable
- Training was so long ago it has been forgotten
- Too much of a moving target
- Contradictory information from NAACCR and CDC

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

| Value | | Percent | Responses |
|--------------|---|---------|------------|
| v18 |  | 62.8% | 27 |
| v16 |  | 9.3% | 4 |
| I don't know |  | 27.9% | 12 |
| | | | Totals: 43 |

Has your registry officially suspended reporting timeliness requirements?



Adverse impacts of the delay, as synthesized from comments (each of these was identified by numerous registries)

- Incomplete data leading to artificially low rates
- Data quality problems generally
- Delay in mandated reports
- Delay in scheduled linkages, or incomplete linkages
- Delay in existing and proposed research projects
- Delay in workers' compensation claims
- Expectation of negative press/bad public relations
- Need to generate warning messages to attach to all files/reports/analyses

The survey results were shared with the NAACCR Board of Directors, the Mid-Level Tactical Group and the High-Level Strategic Group. The survey indicated that fewer than 5% of the expected number of 2018 cases had been processed by central registries in March of 2019. Based on the information provided in this survey, the High-Level Strategic Group made the decision not to implement any changes in 2020, to allow hospital and central registries to catch up on backlogs created as the result of the long delay in releasing data changes for 2018. This also allows for more registrar training and ability to become familiar with the nuances of the large number of new data items.

This survey implemented by the NAACCR Standardization and Registry Development Steering Committee demonstrates the value of monitoring and tracking of any major data changes implementation, so that careful consideration can be given to the impact on hospital and central registries. A follow up survey will be conducted at a later date to further monitor the progress of central registry readiness to accept and process 2018 cases.