

Summary Report

NAACCR Central Registry Readiness for 2018 Data Changes Implementation Survey – Part III

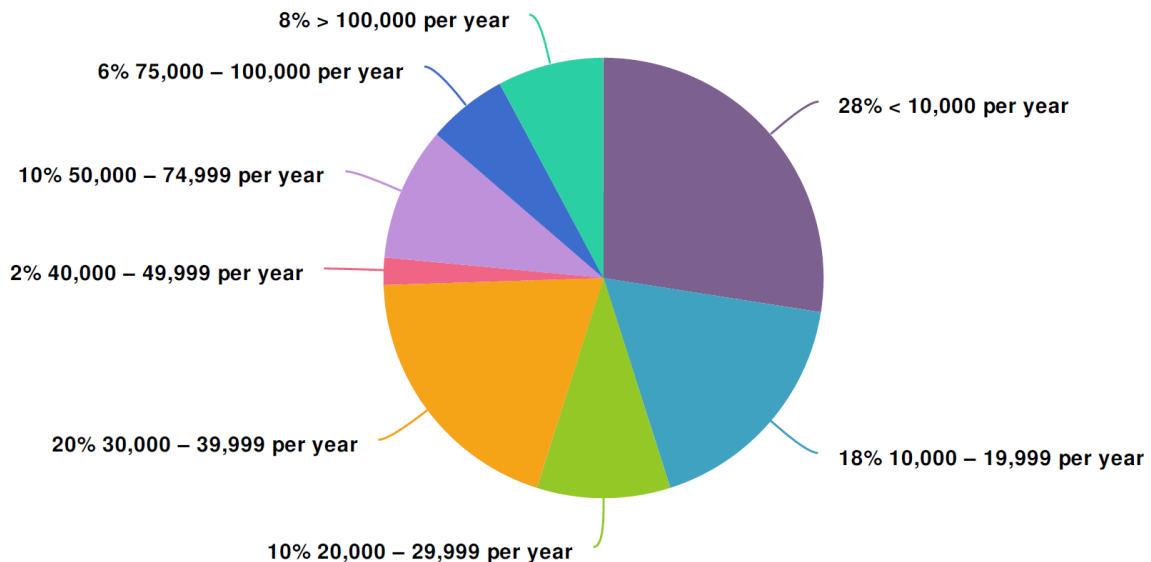
In an ongoing effort to assess how prepared and ready central registries are to accept and process 2018 data, the NAACCR Standardization and Registry Development Steering Committee (S&RD SC) developed a series of online surveys. The initial survey was distributed in March of 2019, with 39 responses from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

The third survey was distributed in May of 2020. A total of 50 survey responses were received, with 44 responses from U.S. registries and 6 responses from Canadian registries.

Frank Boscoe, who conducted the analysis of the previous survey responses, also conducted the analysis for the third survey responses.

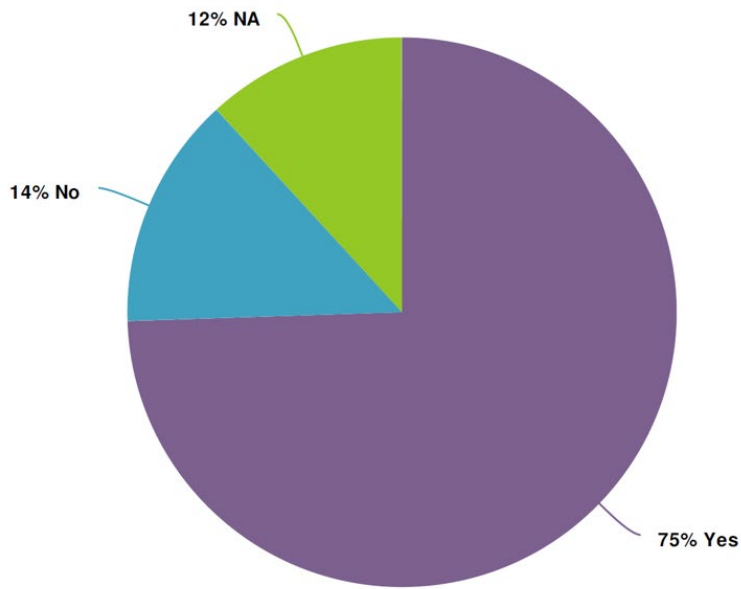
Here are the highlights of the third survey results:

Annual Case Volume:

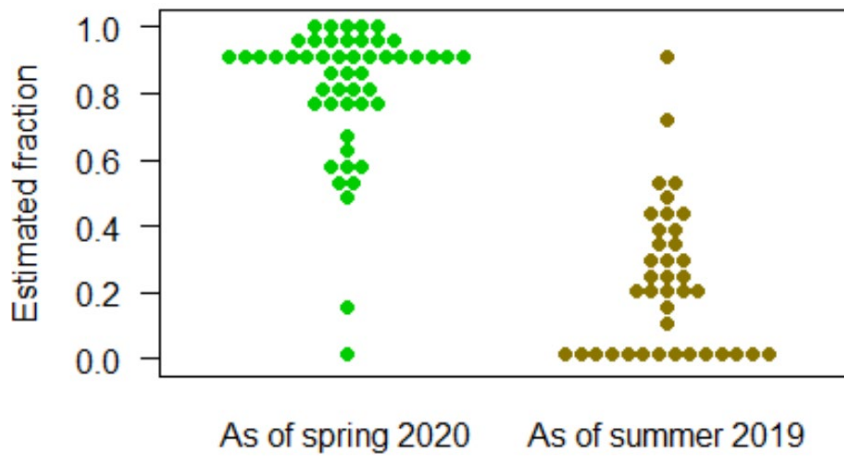


2018 Status as of May 1, 2020

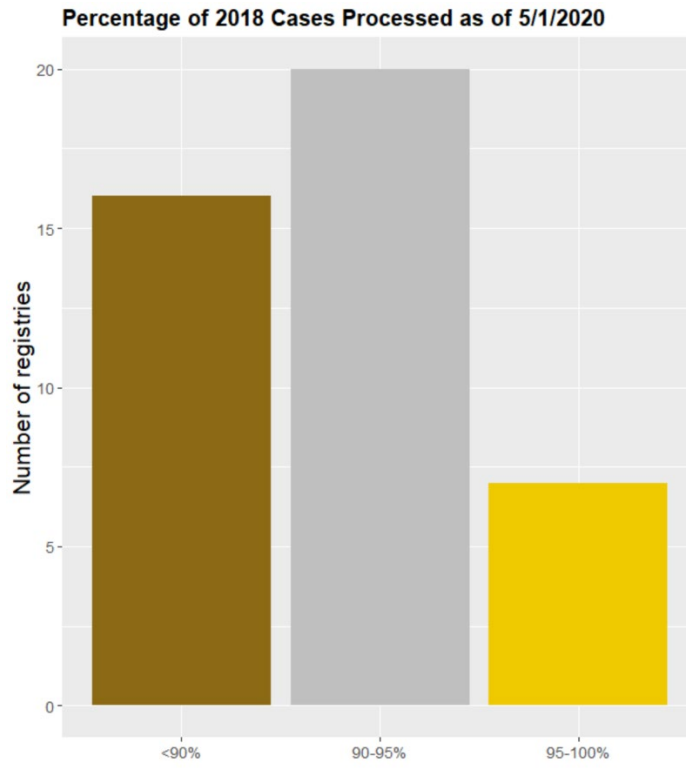
1. Are any of your hospitals less than 50% complete for 2018?



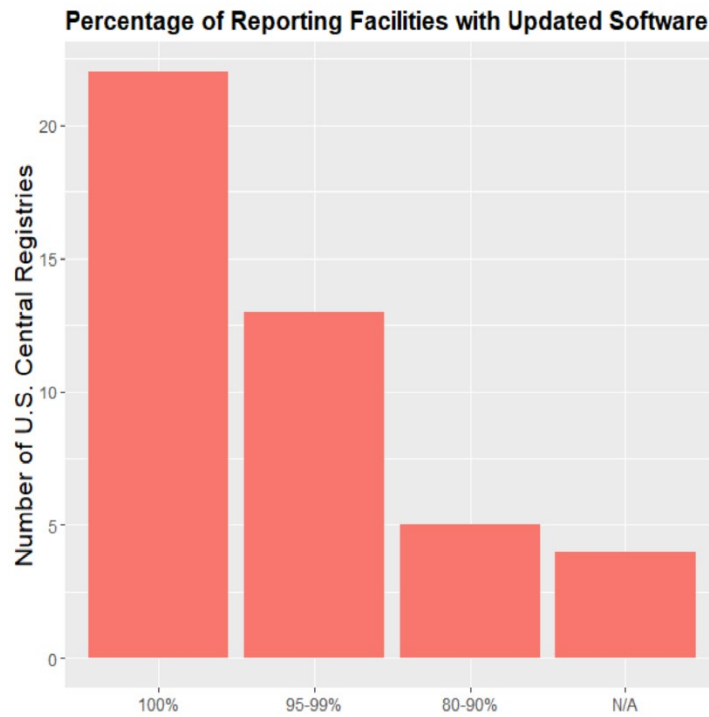
2. How many 2018 cases have you processed so far? (as a percentage of expected cases)



3. How many 2018 cases have you processed as of 5/2/2020 (as a percentage of expected cases)?



4. For U.S. Registries, what percentage of your reporting facilities have updated 2018 software?



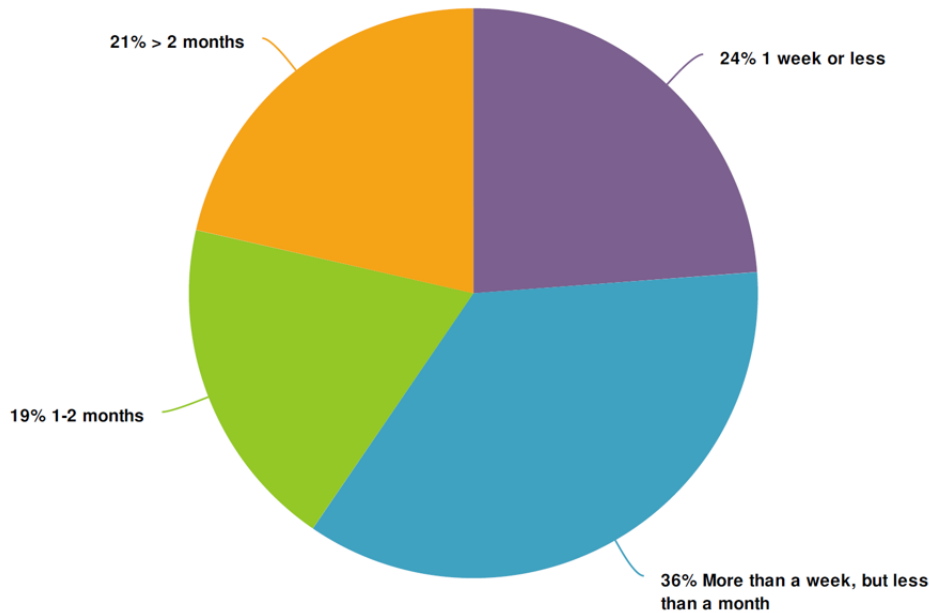
5. For Canadian registries only, have you received and implemented your vendor software as of 5/1/2020?
- Yes- 4
 - No-2

EDIT Metafiles

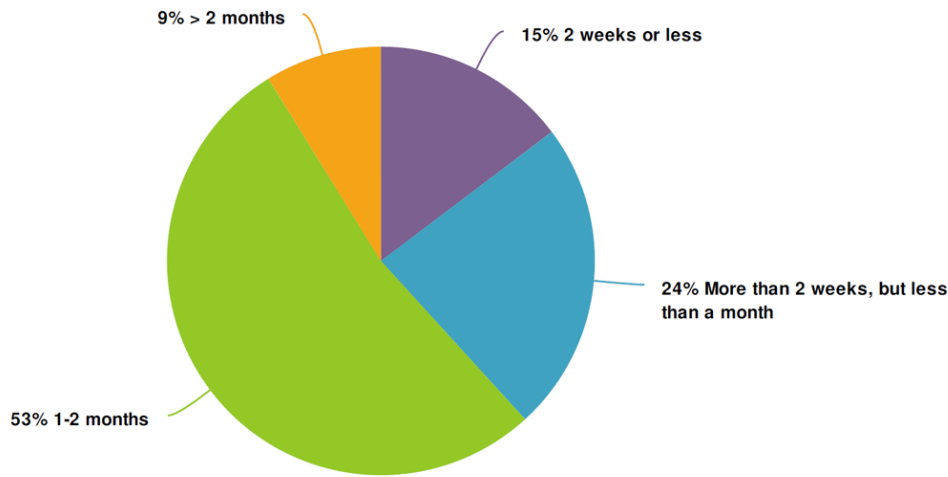
1. Has your central registry finalized the v18 Edits Metafile for distribution to reporting facility software vendors?

	Yes	No	No response/ Not applicable
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%)

2. Approximately how long does it take to update and release your state specific edits metafile after a new or updated NAACCR Edits metafile is released?



3. Approximately how long does it take for reporting facilities to start using an updated state specific edits metafile once it is released by your registry?



XML Status and Understanding

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

- Yes- 66%
- No- 34%

2. Do you know where to find resources for the NAACCR XML Standard?

- Yes- 94%
- No- 6%

3. Are you aware that all central registries that require state-specific data items need to provide an XML User Dictionary defining those items to reporting facilities and software vendors?

- Yes- 75%
- No- 25%

4. If you require state-specific data items, do you know where to find the tools to create an XML User Dictionary for those items?

- Yes- 70%
- No- 30%

5. Have you reviewed the NAACCR XML Data Exchange Standard and documentation located on the NAACCR Website?

- Yes- 67%
- No- 33%

6. Do you understand the NAACCR XML Data Exchange Standard requirement for v21?

- Yes- 64%
- No- 36%

7. Is there any additional information that would help you understand XML and how it will impact your registry for NAACCR v21?

- Yes- 33%
- No- 67%

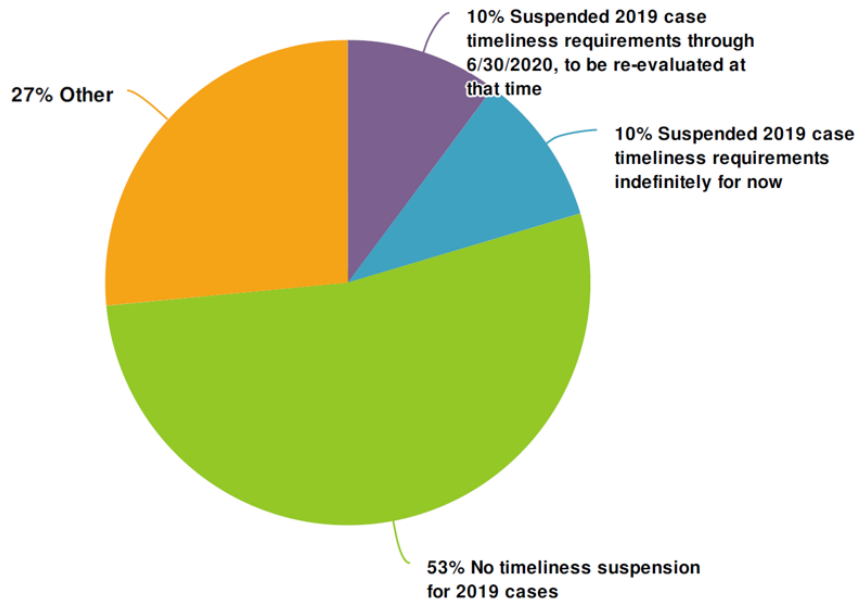
2019 Status as of 5/1/2020

1. As of 5/1/2020, what is your registry completeness for 2019?

Value		Percent	Responses
0% (If 0%, please explain)		6.0%	3
1 - 25%		26.0%	13
26% - 50%		54.0%	27
51% - 75%		12.0%	6
86% +		2.0%	1

2. For 2019 cases, has your registry officially suspended reporting timeliness?

The majority of the “other” responses were due to the central registry not having an official timeliness requirement or the leverage to enforce. Other examples revolved around encouraging hospitals to do the best they can.



2019 Call for Data File Submissions

b. Regarding the 2019 Call for Data NAACCR and NPCR submission files, your registry:

Value	Percent	Responses
Submitted the same cases for 2017 and 2018 to both NAACCR and NPCR	56.1%	23
Submitted the same cases for 2017 to both NAACCR and NPCR, but updated 2018 cases to NPCR (more cases added to 2018 NPCR file)	12.2%	5
Submitted updated cases for both the 2017 and 2018 files to NPCR (more cases added to NPCR 2017 and 2018 files)	31.7%	13

Comments

This most recent survey included several opportunities to provide comments. The comments related to XML were provided to the XML Workgroup, comments concerning edits were provided to the EDITS Workgroup and comments concerning education and training were provided to the Professional

Development Steering Committee. The remaining comments were separated into the following categories, summarized, and included as appendices to this report:

- *Impacts of Data Quality: Appendix A*
- *Impacts on Registry Operations: Appendix B*
- *Impacts on Other Funded Projects: Appendix C*

Summary

Based on the responses from 50 registries, central registries have made good progress in their ability to accept and process 2018 cases since the first two surveys was conducted. There are now 34 registries that have over 90% of their 2018 cases completed. Reporting facilities are now better positioned to report 2018 cases. Thirty-nine US registries indicated 80% or more of their reporting facilities have 2018 software. Of those, 22 indicated all their facilities have 2018 software. Four of the six Canadian Registries have implemented the vendor software.

The v18 Edits metafile is now implemented in the majority of the central registries. Sixty-nine percent of respondents indicated they have distributed the v18 Edits Metafile to the reporting facility software vendors. Sixty percent of the respondents are able to prepare Edits Metafiles in a month or less. Nineteen percent need 1-2 months to prepare the metafiles and 21% need over 2 months to prepare the metafile. Once the software vendors receive the metafiles, 39% of the registries indicated reporting facilities start using the new metafile within a month or less, 53% take 1-2 months and only 9% take more than 2 months to start using the new metafile.

A portion of the survey focused on XML readiness. All in all, the majority of the registries reported they are ready to implement XML for 2021 cases. Sixty-six percent indicated their software can process XML files. Most registries understand the XML Data Exchange Standard (64%), know where to find resources (94%) and know what is needed to continue to collect state-specific data items (75%). Only 33% indicated the need additional education.

Registries have been able to start processing 2019 cases as well. Only 3 registries indicated they have not processed any 2019 cases. The majority, 27 registries, indicated being 26%-50% complete for 2019 cases. Only one registry indicated they are over 86% complete.

Registries were also asked about cases included in the 2019 Call for Data file submissions to NAACCR and NPCR. The majority of the registries reported the same 2017 and 2018 cases to both NPCR and NAACCR. Five registries submitted the same 2017 cases to both NAACCR and NPCR but added 2018 cases to file submitted to NPCR. Thirteen registries added additional 2017 and 2018 cases to file that was submitted to NPCR.

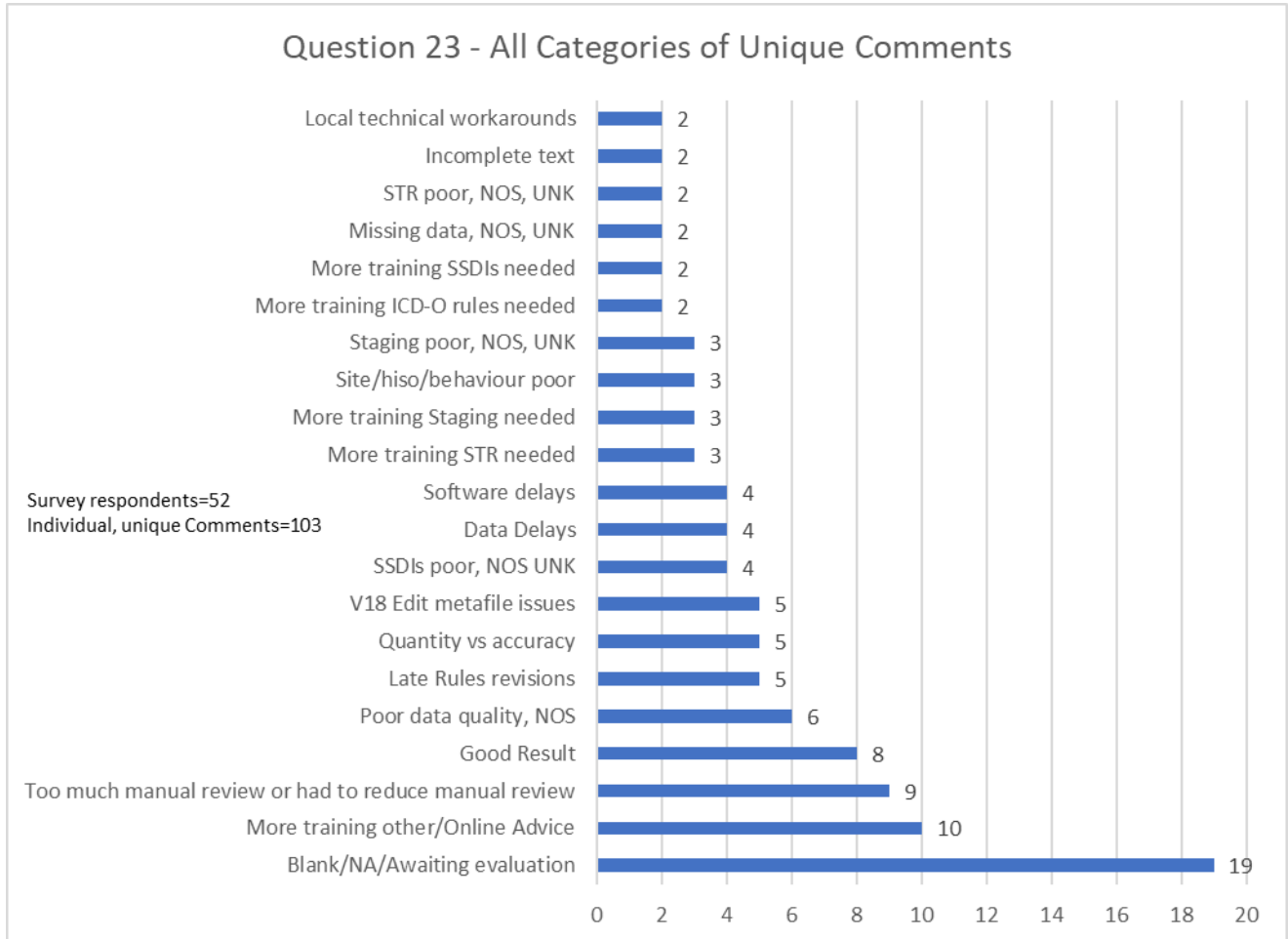
NAACCR will continue to monitor the effects of the delay and recovery period. The next survey is scheduled for release after the 2020 Call for Data submissions.

Appendix A: Describe the impact of the 2018 data changes on data quality

Fifty-two respondents participated in this iteration of the 2018 Readiness Survey. Nine of the respondents did not respond to this question (counting “N/A” as blank). Ten made statements equivalent to “awaiting evaluation”, sometimes in combination with other observations. Of the 43 respondents who provided meaningful content, the reviewers grouped these comments into 21 categories (with Blank/NA/Awaiting evaluation always concatenated), equaling 103 unique observations. We have attempted to categorize the observations fairly, but review of narrative answers must always be somewhat subjective.

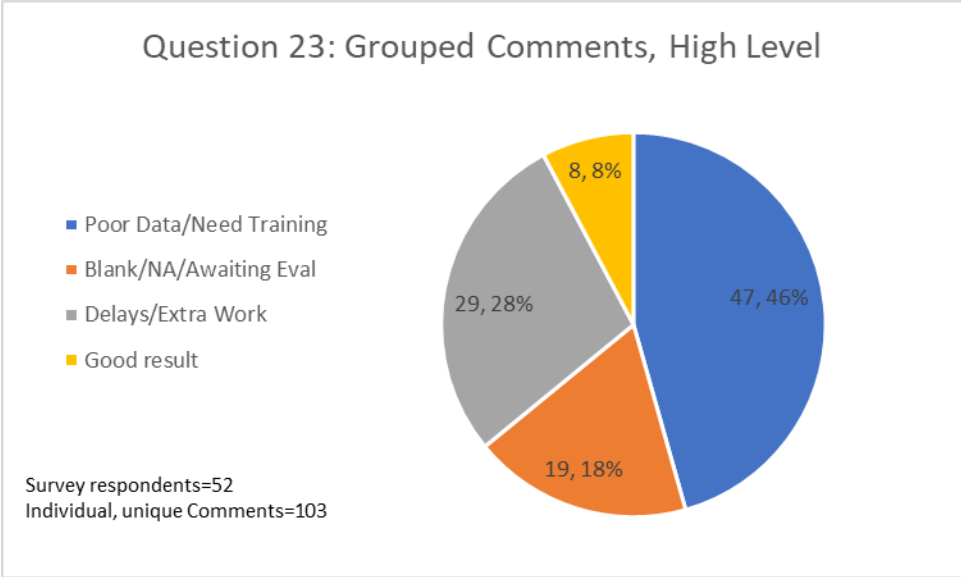
1. More training STR needed
2. More training ICD-O rules needed
3. More training Staging needed
4. More training SSDIs needed
5. More training other/Online Advice
6. Missing data, NOS, UNK
7. Site/hiso/behaviour poor
8. STR poor, NOS, UNK
9. SSDIs poor, NOS UNK
10. Staging poor, NOS, UNK
11. Incomplete text
12. Late Rules revisions
13. Quantity vs accuracy
14. V18 Edit metafile issues
15. Poor data quality, NOS
16. Data Delays
17. Too much manual review or had to reduce manual review
18. Local technical workarounds
19. Software delays
20. Good Result
21. Blank/NA/Awaiting evaluation

The number of instances of these comments, arranged by frequency, is shown in Graph 1:



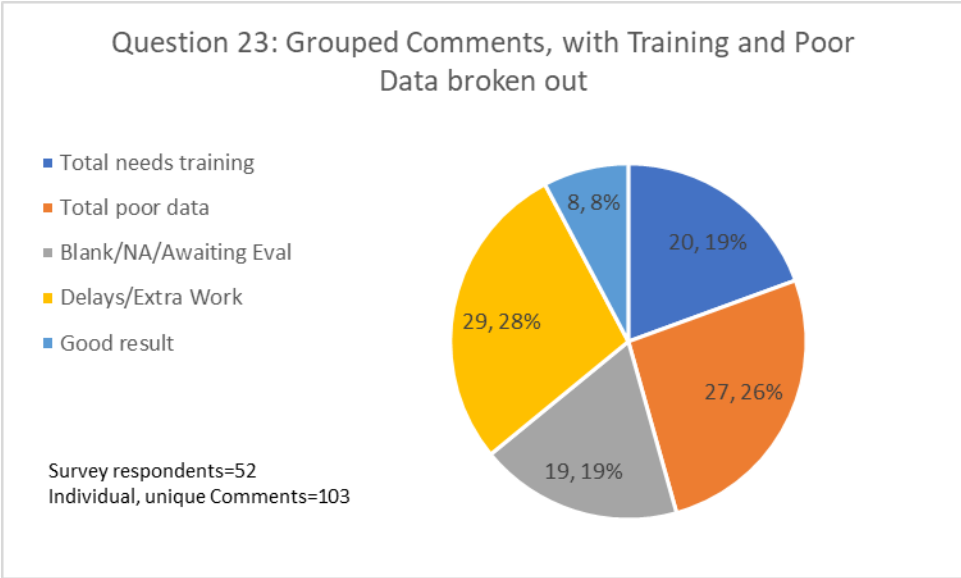
Graph 1

At the highest level, see Graph 2, the findings show that that almost half of the issues concerned poor data and a need for training on new rules. Over a quarter of the comments referred to problems of delays and extra work, almost 20% variously did not answer or said they were awaiting evaluation. Under 10% reported a good outcome. It is also important to note that the grouped category, Delays/Extra work, includes a wide set of issues: too much/too little manual review, late rules revisions, V18 edits issues, data delays, software delays, and (the need for) technical workarounds. The point is that, while the number of each of these types of comments was small, they added up to a significant portion of the concerns expressed by respondents.



Graph 2

The third and final graph shows very similar results but with training needs broken out from observations concerning poor data, with the latter being mentioned more frequently. However, it is important to note that many respondents packed several observations into one response, including training and poor data in some instances. Also, in the minds of registry respondents, it may be a common sense “given” that the two are connected, even if both are not mentioned.



Graph 3

Cancer surveillance standard setters may wish to take note of the following data quality comments. Areas causing confusion, training suggestions, notice of expected delays, anticipated data quality problems, and other observations are listed.

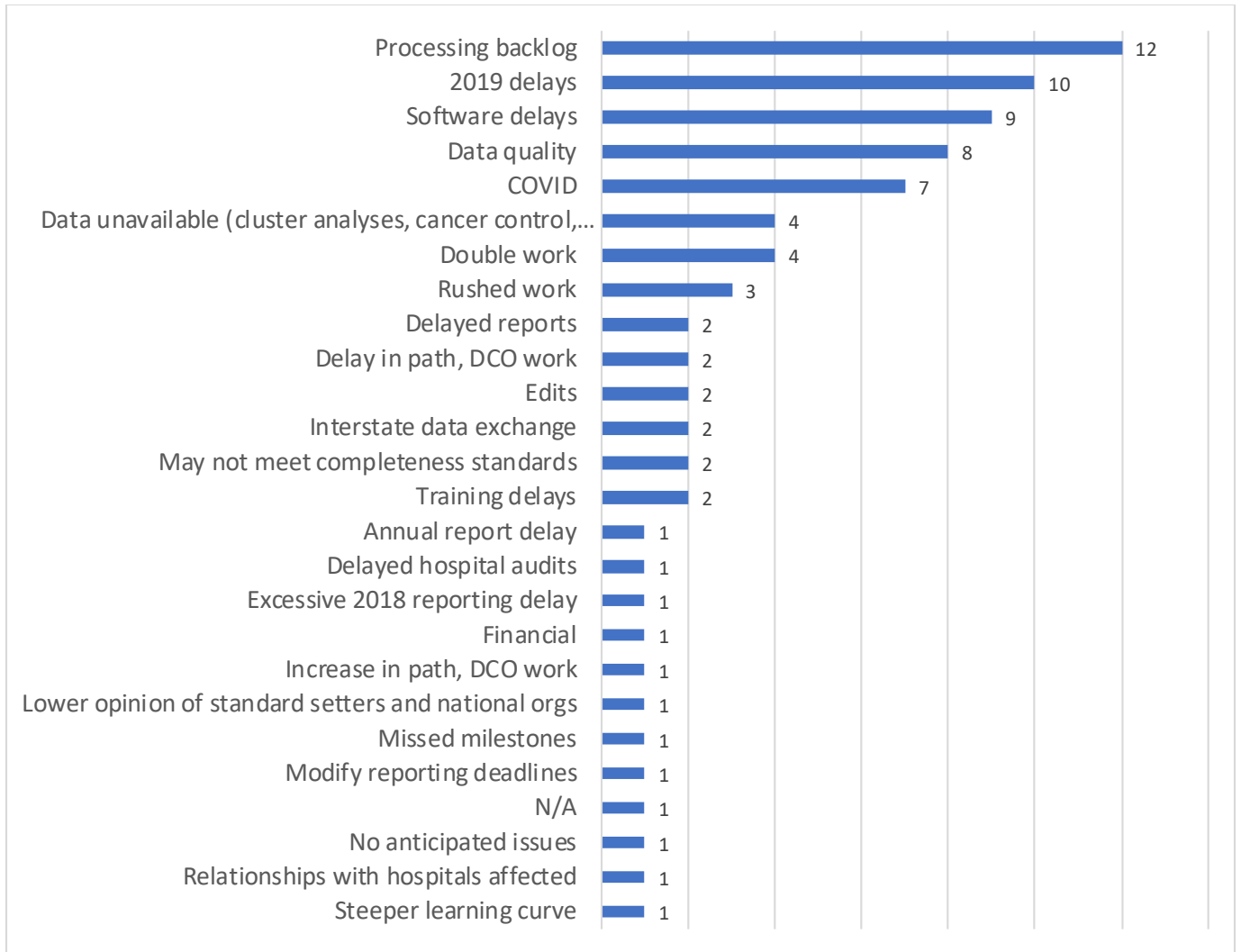
- Training needed on new rules
- Data quality issues with 2018 stage data expected
- Multiple changes/revisions to the manuals cause of confusion, frustration
- CAnswer Forum not user friendly to search
- 2018 edit metafile insufficient, does not catch all errors, requires manual review
- Suggest looking at outliers of coding for SSDIs
- Staging impacted by lack of edits
- Delay of training on solid tumor rules caused re-coding of path reports
- Unlimited text takes longer to review for accuracy
- Confusion on data elements that derive NPCR stage
- Confusion on ICD-O codes
- Confusion on solid tumor rules
- Multiple version of edit file caused extra work for central registry
- Deletion of AJCC TNM data will decrease researcher and physicians' ability to request data and compare data across diagnosis years
- Increased number of rejected files due to hospitals using an outdated version in their registry software, resulting in potentially unreported cases

The NAACCR membership may be interested in the following data quality comments. These are points to be aware of while working with 2018 cases and 2018 data.

- Not using manuals, online resources
- Too many NOS/Unknown codes assigned
- Long learning curve for new data items
- Need new visual review processes
- Incorrect coding of histologies
- Lack of text documentation
- Errors in Summary Stage coding
- Errors in applying solid tumor rules
- Errors in coding grade
- Some hospital and contract registrars not up-to-date on how to abstract 2018 data

Appendix B: Describe other factors or functions impacting your registry operations as the result of the 2018 implementation delay.

There were 48 comments for this question which contained some common themes. These could perhaps be distilled further, but 26 themes emerged. These are listed below with the number of respondents that mentioned them. Some respondents' comments contained more than one theme.



Appendix C: Describe the impact of the 2018 implementation delay on other projects for which you currently are funded.

Areas of projects impacted due to 2018 implementation delay:

- Operations: ~51% (20/39) of registries reported obstacles impacting operations.
- Data Reporting: ~13% (5/39) of registries reported obstacles impacting statistical reporting (publications, reports, products).
- Data Requests: ~38% (15/39) of registries reported obstacles impacting routine or research data requests.
- Education: ~8% (3/39) of registries reported obstacles impacting educational activities.
- No Impact Noted: ~18% (7/39) of registries reported no obstacles.
- Don't Know: ~2.5% (1/39) of registries reported unknown impacts.
- Detailed Summary

Operations (where 'project' is likely contract with SEER, NPCR, or other major funder)

- Difficulty meeting Call for Data requirements – completeness, quality, timeliness
- Delay linkages or linking fewer cases
 - Death certificates, NDI, screening programs
- Delay outreach to outpatient, physicians, labs
 - Casefinding
 - Conversions to electronic reporting
- Delay follow back activities: death clearance, path only
- Training (internal & external)
- QA/QC reviews (internal & external)
- Facility audits

Ability to provide complete or high-quality data to researchers, projects, other departments delayed or incomplete

- Some not releasing any 2018 data yet
- Missing or not releasing stage, treatment data
- Research data requests

Delay registry and/or health department publishing cancer statistics and reports

- Significant delays in provincial health care quality indicators (Canada)

Research projects

- Traditional case ascertainment/sampling low and repeated sampling may be needed
 - Cohorts sampling from 2018 may be biased
- Rapid case ascertainment not initially affected, but delayed release of complete case information

Specific impacted projects mentioned:

- SEER Patterns of Care (POC)
- RESPOND Study
- Medullary Thyroid Carcinoma Surveillance Study
- NPCR Component 2 projects
 - Biomarker Data (NPCR Prognostic Factors)
 - Breast and Cervical Cancer Screening pilot
- CDC Data Quality Evaluation
- VPR (Virtual Pooled Registry)
 - Fewer 2018 patients in linkage file
- Cancer control activities
 - Cluster investigations
 - Screening programs
 - Compensation claims for patients