**2019 Program Review Current Realities and Future Needs Breakout Sessions**

**Flipchart Notes**

**Current Realities**

V18 Delays:

* Impact hospital reporters
	+ Redo process delays
* Changes in submission calendar (double-duty)
* Postponement in data submission
	+ Limited time for consolidation
* Need to “nix” something due to limited time (choosing quality? Timelines?)
* Quarterly feedback reports to facilities not sent
* Hospital registries have questions about edits (issues supporting them)
* Rely on hospital registries (additional burden)
* How are SEER dealing?
* Issues w/ timeliness🡪 late award certificates
* Not much sense of where hospital registries are
* Vendor released without 18 edits
* Questions from hospital supervisors/management. About time to catch up
	+ Want something in writing
	+ Send formal revised calendar
	+ Discuss that it’s a national problem
* Identify which might create new tumor cases (incoming abstract links to patient automatically)
* Prioritize certain statuses in case consol., etc.
* Maybe Reg. Plus (CRS Plus) can identify new case or existing for update (suspense database)
	+ Link between eMaRC Plus and CRS Plus for path & physician
	+ Web Plus
	+ Can do through linkages 🡪 time consuming? SAS program?
* Test conventions- test meta file and distribute to hospitals
	+ \* beta test real cases from hospitals
	+ Feedback loop
	+ Parallel system (RMD)
* Use path. Report to create NAACCR abstract
* Similar to 16 strategy
	+ Ensure hospitals about *not* “beat them over head”
* Notified leadership about situation (set expectations early)
* Charge hospital a fine for delayed reporting
	+ Enforce this more?
	+ Find out which states can fine
	+ Pull certificate of need

**Future Needs**

* Use Web Plus- develop in-house script (small data cases)
* Random 10% text to code review difficult to achieve, detailed case-by-case feedback (target site each month)
* Submit as non-NAACCR files, give gen-edits
* Focus on field (non-COC) hospitals first (75%)
	+ Can Web Plus or another component of Reg. Plus address
* Start OCO cases early on
* Perform pending case linkages first
* Path only- may be too much work, so wait (NAACCR abstracts first)
* Focus on 18s for Oct.
* Eliminating something (national impact? If individually choosing)
	+ NPCR decision?
		- State situations depend
	+ FW on to national without QA
		- Understand bad year and move on to next year
	+ Sacrifice 18 for better 19 data
	+ Skip one year for USCS
* Issue may not be that “we don’t want changes”, but changed in more organized way as standard setters (learn from 2010 changes, 18 delays)-prevention
* Need standard setters to unite and develop organized process
	+ Not leave up to reg. to work around, etc.

**Data Elements Requested in State**

* Staging AJCC
* Treatment
	+ Completion status
* Biomarkers- BRCA
* Health behaviors
	+ Smoking
	+ Alcohol use
* DMV- weight, BMI
* Disease progression & recurrence
* Family hx
* HPV
* Comorbidities
* Screening
* Distance to care
* Census tract
* SES
* Linkages to Medicaid/medicare
* Hot spots for radon
* Cancer clusters
* Linking to dept of labor occupation
* Triple negative status
* Reconstructive surgery for breast cancer
* Drug information
	+ Type of chemo
	+ Oral
* Screening and behavior @ catchment area
* Fire fighters
	+ NIOSH - 2020

**Data collected for Future**

* Data not being used/complete
* Data items not vetted
* Some hospitals hide data items
* Treatment data quality
	+ 6 months
	+ Study – 15 month resubmission anything that had to be changed
	+ Big change but a lot of work
		- New treatment- changes from no treatment to treatment
		- Hormone therapy
* Pilot testing rapid data
	+ Demographic
	+ Treatment and staging
* Still collecting TNM, not collecting EOD
* Colleting EOD
	+ Derived TNM
	+ Not relying on directly coded TNM
	+ Derived SSS
* Collecting
	+ TNM
	+ EOD
	+ SSS
* Not realistic to add new stage
	+ TNM not reliable anymore
* Physician reports
	+ Stage coded upon receipt
* eMaRC records being resent repeatedly
	+ if field missing data locks up
	+ have to manually look up
	+ MU 2
* MU
	+ Extensive testing before put into production
	+ Text mapping
	+ Increases in melanoma

**Missing Resources & Needs**

* Staffing
* Primary *otc?*
* Automating
* Education tool on how to home grow CTR
	+ NAACCR?
	+ Physical vs online
		- Community colleges
		- Marketing career path
		- Mentoring – personal component
* Need: rules of engagement
	+ Major/minor change process
		- Standard setters stick to process
* Abbreviated abstract process/edit
	+ Like DCO
* CTR education/recruiting
	+ Requirements very restrictive
		- Amount of hours
		- Education
	+ Make it easier, remove barriers, appealing
	+ Separate credentials
* 1 place to keep all manuals together for everything
	+ Steps through all levels without going through all manuals

**What data elements are researchers/policy makers requesting?**

* + CA: Treatment data and recurrency/progression
		- (How good is data? No standard definition)
		- \*COC vs non-COC data – quality issues
	+ RI: More sub county geographic data grouped city/town data.
	+ KS: Stages of dx (AJCC) (TNM capture from COC facilities)
	+ MI: Family history, alcohol and tobacco use
		- Changing data collection tools
	+ UT: Genomic data- requiring 6 new (state spec) genomic variables collected from hospitals
	+ OH: Tobacco history- should consider collecting nationally and have clear guidance on collection
		- Staging data- best collected from chart for quality data
		- Issues in capturing genomic data from medical records. Some tests easier to collect than others.
	+ TX: Patient contact info for survivors (address, phone, etc.)
	+ WV: Conflicting info on family history from different sources.
		- Capturing historical addresses for all patients (not doable)
	+ VA: Occupation/industry data: hard to capture and categorize. Just passed law to capture this data. Right questions aren’t asked.
	+ MI: Collection of marijuana use
	+ CA: Survivor/quality of life
	+ OR: Comorbidities/screening data

**What data should be collected for future?**

* + PA: Before adding more data elements need to decide what we should be doing at a state/national level
	+ MI: text fields are requested but these fields end up containing PII (difficult to manage)
	+ OH: Why should cancer registry be responsible for completing linkages for researchers?
		- Some states have restrictions on data release
		- Who is paying for this work?
	+ PA: Should think more about how data are collected before picking new data elements to collect
		- Evaluate systems to identify better systems to capture better quality data (treatment)
	+ OH: SEER states collect more data and follow patients over time.
	+ UT: Links all payer claims data and other processes to get better data. SEER states looking for ways to automate, but will allows require manual review.
	+ CA: Burden on abstracts to collect data- if data aren’t being used then it should be removed.
	+ TX: Need *good* demographics and cancer dx with stage data
		- NPCR registries could benefit from linking with Medicare data (to enhance our data)
	+ KS: Provide clear expectations to researchers about which data elements are good and which aren’t.
	+ PA: Identify what info is more important to know- may need to change definitions to capture information/coding
	+ WV: Capturing TNM from COC facilities but aren’t using it now.
* Challenges:
	+ Benefits of EOD 🡪 gives derived TNM stage
		- No data to know if there is benefit
	+ UT: EOD is simple and easy to capture. COC isn’t required to report EOD.
	+ MI: EOD is way easier than CS and TNM. Training of abstractors is much more straight forward.
	+ PA: If we collect EOD, then this will increase work on abstractors because they will still have to stage according to TNM.
	+ DE: So many issues in 8th edition that AJCC isn’t sure how to deal with. It may be helpful to have EOD to use.
	+ NE: Cancer surveillance data should focus on a minimum set of data.
	+ MI: Need to define what registries do well. Evaluate what we currently collect, what isn’t needed, and make those changes to get best data for our needs.
	+ PA: Stop gap needed to stop 7th edition from 8th edition.
	+ OH: Need a staging field that can be used by researchers. Evaluation of staging data is needed. Simple stage field is needed. Summary stage is very useful.
1. Data elements from researchers/policy makers:
	* Don’t know/aware of data- stage?
	* Outcome details-most common
	* Educate researchers
	* Family history (age); smoking hx; recurrence; sub. tx
	* AJCC-1 stage/person
		+ EOD 🡪 TNM stage group is useful
	* Body mass 🡪 not usual/useful
	* Chemo details 🡪 type, regime
	* Co-morbidities - ? quality
	* MSI
	* HPV status – hard to find
	* Stop 🡪 Occupation/Industry
2. MSI
	* Biomarkers – is popular
	* Burden of finding info (~2 hs/case)
	* What are key items for informed decisions:
		+ Benefit 🡪 cost/burden
		+ Availability/reliability
		+ More clinical info
			- Linkage National Lab 🡪 biomarkers
			- National HPC, etc. linkage
	* How to get data
		+ Add to legislative rules – linkages
	* Positions needed:
		+ Data analyst/GIS – X-training
		+ Geocoding software

EOD advantages

* Derive SS
* Evaluate parts
* Limit SSDI

Resources:

* GIS Specialist
* Time to QC data for geocoding
* Lexus Nexus
* Grade - ? new items
* Molecular Markers
* Chemo details/dates re: neo advent
* ER/PR Her2 – yes
* SS#- leaving Med Rec
* Medicare ID- unique to pt
* Partial # doesn’t work

New Data Items

* Biomarker 🡪 Future
	+ Look at top cancers
* Impact to collect
* How will data be used
* Impact on data collectors
	+ Healthcare Economists 🡪 show benefit to hospital
* Make CTR profession more visible (discuss Executive Director-NCRA; 1-3 exp. is **difficult** 🡪 grow your own CTR
	+ Needs standardized degree program
* Send questionnaire to each program re: frequency/use of biomarker
* Facility report: link with reg. data
	+ 1 pager- what you can use registry for

Q1:

* Using old software, waiting for new version
* Having hospitals submit in v/6, editing to see what issues are to provide feedback
* Have to reject head and neck, better to collect data and reject if need be to see what data are available (feedback)
* Colorado has one vendor that has all cases but waiting for vendors to include in file. As a state have not commented yet
* Hospital version are v/8, metafiles are not included. Run in gen edits first as a way around (Arkansas)
* NJ, cannot export any file. Vendor is electa (sp).
* Vendor needs to be held accountable regarding requirements of software. Data submissions so far are subpar, requires a lot of work from state (NJ)
* Issues with creating metafile (D.C.), data has to be 100% error free = challenge. For D.C. with hospitals closing and consolidation, having data to submit will be a challenge.
* Vermont no 2018 data
* Quality: Fiscal year 18, training did not focus on specific data items. Training for 2018 submission is late
* New CTRs taking exam are tested on v18, state doesn’t have v18 (\*Turnover)
* Issue with suspending audits, look internally
* Missing case data from hospitals
	+ Figure out internal way to make sure data are accurate
* Is 95% completion good enough? Should be 98% for 2017
* Performing 2017 audits should help with 2018 back log (AL)
* GA has backlog, we need to relax completeness due to changes. Consider it a limitation for 2018. In future 2018 submissions may look better but stress needs to be reduced
* Data from pathology should be electronic
* Submit pdf from dermatology facility (?), hire abstractor
* Consider high turnover when auditing and examining cases
* Hire consultant, outside help, focus on core data items
* Frequent change in manuals (only 3/13 available, all from SEER)
* Vendors not making available certain items (radiation)
* NAACCR
	+ 16 revisions on manuals, ICD-O changes
	+ Reduce # of changes
* Florida 120,000 cases behind. Metric, ERS have not received cases from vendors
* \*Stop or limit changes
* How long will it take to get back to normal schedule?

Q2/3: postpone 2017 hospital audits

1. Solutions (Sarah M.)
	* Cheat sheet to share
	* Prioritize measures and task reporting
	* Flexibility for….?
	* Blogs [across board communication]
	* FLccSc
	* Send FY17 cases before reporting
	* Death Clearance Timelines
	* Running Files through Meta files at hospital level

Programs

* Suggestions from CDC
* Limited resources [CTR staffing]
* Work around solutions
	+ Project cost
	+ Challenges
	+ Software issues
	+ Remote access
	+ Other funding sources
	+ Down time to do things not usually have time to do
	+ Staff collaboration
	+ Data quality
	+ Shifting job response