**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