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

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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.

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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