INTRODUCTION TO OPEN SESSION

2018/2019/2020

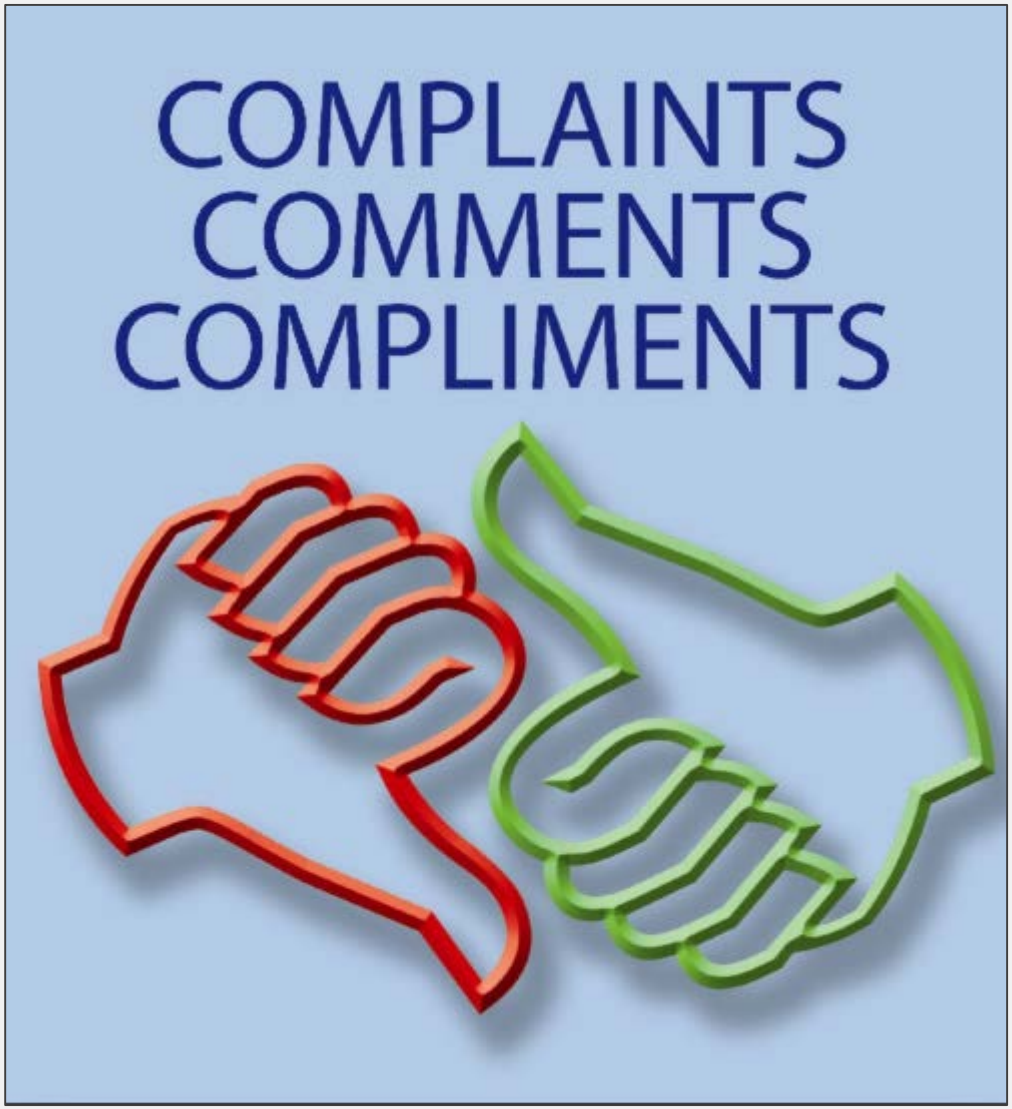
PRIORITIES, DEADLINES, EXPECTATIONS

FCDS Annual Conference

July 31, 2019

Orlando, Florida

Steven Peace, CTR


COMPLAINTS
COMMENTS
COMPLIMENTS

CDC & FLORIDA DOH ATTRIBUTION

"Funding for this conference was made possible (in part) by the Centers for Disease Control and Prevention. The views expressed in written conference materials or publications and by speakers and moderators do not necessarily reflect the official policies of the Department of Health and Human Services, nor does the mention of trade names, commercial practices, or organizations imply endorsement by the US Government."

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SESSION OUTLINE

- **Introduction to Open Session - Standards & Reporting for 2018/2019/2020**
  - S. Peace – FCDS & Central Registry Perspective on Changes
  - NAACCR Survey (March 2019) State Readiness for 2018
  - Training, Software Availability, Abstractor Expectations, Managing and Effect on Deadlines, QC & Data Quality, Use of Contractors, State/National Calls for Data, New Data Items, New EDITS, Priorities, Monitoring Incoming Abstracts

- **CDC NPCR Program – Managing 2018-2020 Changes**
  - L. Douglas – NPCR & National Registry Perspective on Changes

- **Expert Registry Panel – Problems, Delays, Solutions, Hints**
  - H. Burner – 2018 Implementation Effects on Large CoC-Accredited Network Registry - CRStar
  - A. Ruiz – 2018 Implementation Effects on Small Network Registry - CRStar
  - K. King – 2018 Implementation Effects on Medium Network Registry - METRIQ

- **Round Table Open Discussion on Failures/Successes of 2018 Implementation**
  - CNeXT and Oncolog User Feedback on Implementation Effects and your software
  - Cancer Reporting from Non-Accredited Hospitals, Surgery Centers, and Radiation Centers
  - Independent Contract Abstractor and Interim Staffing Companies Feedback on Implementation Effects
  - Summary of Current Status of Florida Registry Reporting to FCDS – Training, Delays, Deadlines, Other Feedback

INTRODUCTION TO OPEN SESSION STANDARDS & REPORTING 2018/2019/2020

- FCDS & Central Registry Perspective on Changes
- NAACCR Survey (March 2019) - State Readiness for 2018
- KNOWN ISSUES: Training, Software Availability, Facility Administration for Production, FCDS Reporting and Abstractor Expectations, Managing Deadlines, QC & Data Quality, Using Contractors, State/National Calls for Data, New Data Items, EDITS, Competing Priorities, and Monitoring Incoming Abstracts
- The Aftermath of Introducing Major Standards Changes in 2018

  2019 Changes // 2020 Changes // 2021 Changes
- Change Saturation and Recommendations for Balancing Priorities

INTRODUCTION TO OPEN SESSION STANDARDS & REPORTING 2018/2019/2020

- ALL 2018 Diagnosis, Treatment, Admissions are due 3/31/2020.
- This includes ALL Analytic AND ALL Non-Analytic Cases
- This includes ALL In-Patient and Ambulatory Care Visits
- 2019 Diagnosis, Treatment, Admissions will not be accepted until 4/1/2020 OR after you have signed that 2018 is 100% complete.
- FCDS will follow-back on your completeness when we do our 2018 AHCA/Mortality Follow-Back and Facilities who have signed 2018 as complete but are less than xyz% complete on AHCA will be penalized and will not receive Jean Byers or Pat Strait Awards.

FCDS & CENTRAL REGISTRY PERSPECTIVE ON CHANGES

START SENDING FCDS YOUR 2018 CASES IMMEDIATELY

FCDS is currently 150,000 cases behind in receiving 2018 cases from Hospitals.

We only have until 2021 to get caught up with abstracting and processing before things change again…

The FCDS Abstractor Code Test, FCDS EDITS, and FCDS QC Reviews can only go so far to check on proper use of new manuals, new instructions, new codes, overuse of NOS codes, whether or not they are following all of the Florida Rules, etc.

Use CAUTION when hiring interim staff, contractors, or contract staffing agencies to help with backlogs. They often use brand new CTRs unfamiliar with Florida Requirements particularly FCDS TEXT REQUIREMENTS WITH DATES and reporting historical cancers, they often have limited training, and provide limited if any supervision or instruction on using new manuals/rules or when data quality problems crop up.

You are ultimately responsible to monitor their data quality, completeness, casefinding, not reportable cases for AHCA, etc. If you do not keep an eye on their data quality – you will be making lots of corrections after they are gone.

FCDS can only do so much to identify problems.

NAACCR SURVEY (MARCH 2019) CENTRAL REGISTRY READINESS FOR 2018

Are you able to receive 2018 cases right now (March 2019)?

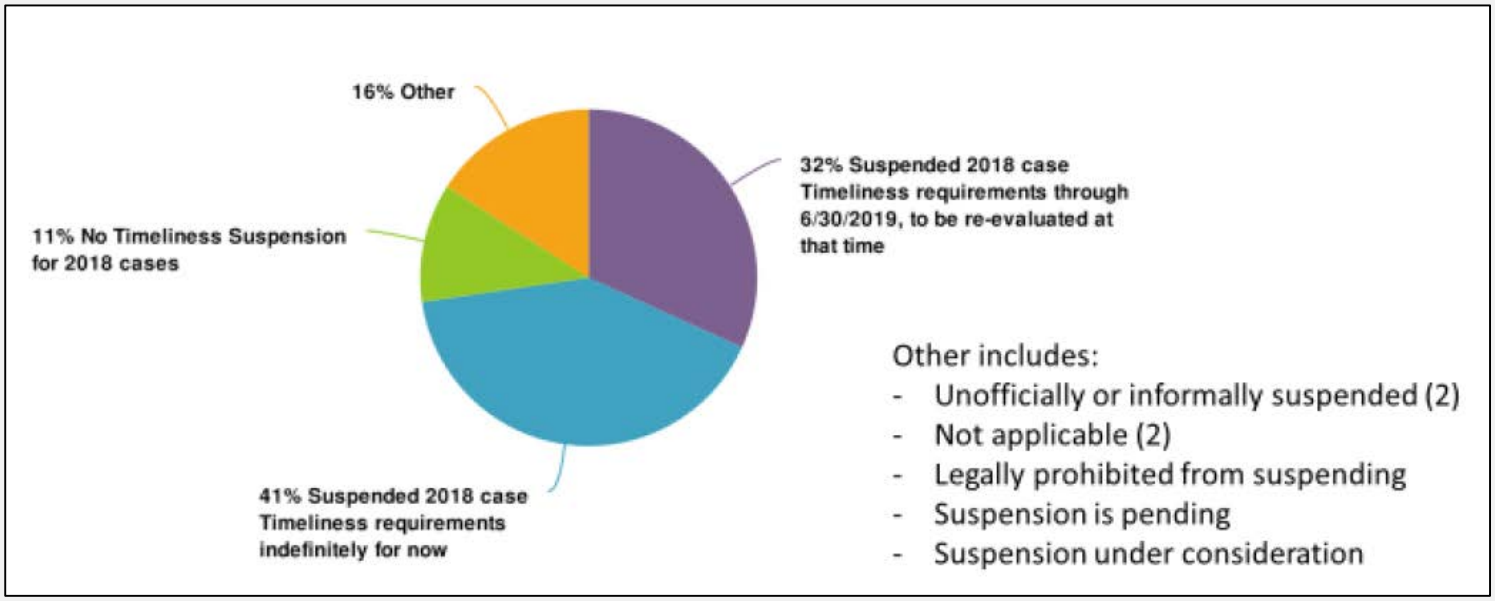
	Yes	No	Don't know/ didn't answer
SEER*DMS	9	0	1
Registry Plus	2	13	0
Rocky Mountain	4	5	0
In-house	5	2	0
Other	0	3	1
TOTAL	20 (45%)	23 (52%)	1 (2%)

Are you able to process 2018 cases right now (March 2019)?

	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%)

NAACCR SURVEY (MARCH 2019) CENTRAL REGISTRY READINESS FOR 2018

Has your registry suspended reporting timelines requirements?



NAACCR SURVEY (MARCH 2019) CENTRAL REGISTRY READINESS FOR 2018

Has your registry been able to assess training needs/issues?

Why Not?

- Impossible to assess training needs until 2018 case processing begins. Only then will we have the data necessary to provide feedback to registrars, trainers, and state registries that will enable us to assess how well registrars learned requirements, new data items, new codes, new rules and new instructions.
- Posted webinars are outdated and instructions changed.
- Solid Tumor Rules in particular are questionable and have been updated numerous times and again for 2019…very confusing!
- Training was so long ago it has been forgotten.
- Too much of a moving target as requirements, standards, instructions, manuals, and information from trainings keep changing and there is no one central repository for info.
- Contradictory information from NAACCR, CoC, and CDC

NAACCR SURVEY (MARCH 2019) CENTRAL REGISTRY READINESS FOR 2018

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

KNOWN ISSUES "PROCEED WITH CAUTION"

- Training Issues
- Software Availability
- New Data Items Required
- Volumes of New Manuals/Instructions
- FCDS EDITS Metafile and National Metafiles
- Monitoring & QC of Incoming Abstracts
- Managing Expectations
  - Facility Administration for Production
  - Competing Priorities - CoC and State Registries
  - NCDB and RQRS for Approved Cancer Programs
  - FCDS Reporting and Data Quality Expectations
  - NAACCR and CDC NPCR Calls for Data
  - Abstractor Expectations – time, priorities, management, oversight
  - REMOTE ABSTRACTORS have little to no oversight but still need it.
- Managing Deadlines – Florida & CDC Deadlines + NCDB & RQRS Deadlines
- APPROACH With CAUTION – Using Contractors & Interim Staffing Organizations

THE AFTERMATH OF INTRODUCING MAJOR STANDARD CHANGES - 2018

2019 AND 2020

On April 4, 2019 cancer surveillance leadership from the ACoS Cancer Programs, the Canadian Council of Cancer Registries, NAACCR, NCRA, NPCR and SEER met to discuss potential changes in cancer surveillance data collection for the calendar year 2020.

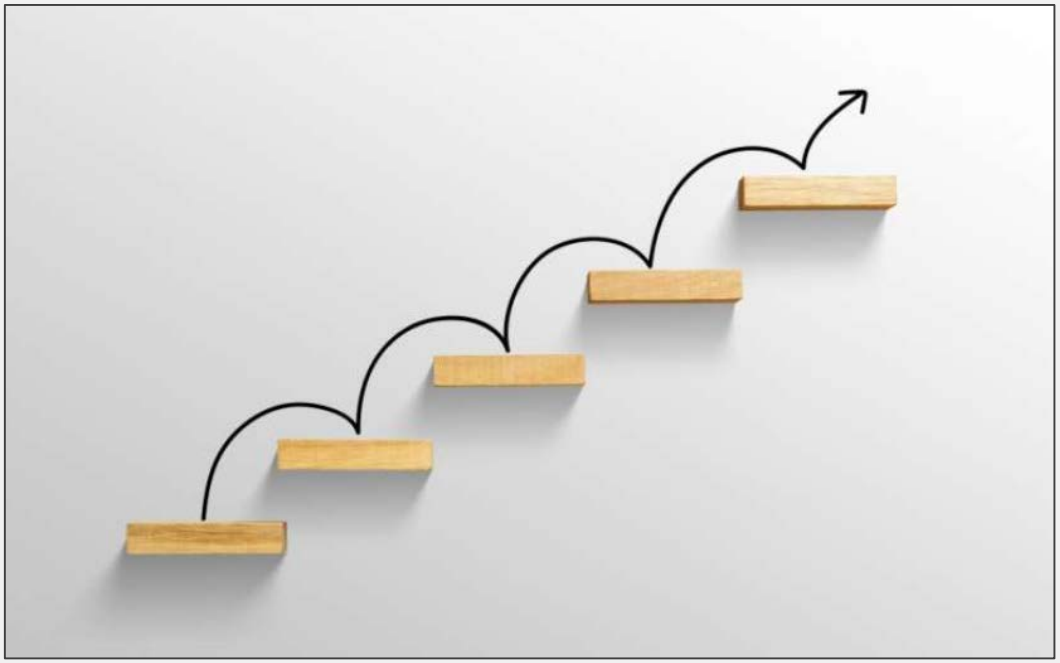
Considering the significant delays in the capacity of registries to process 2018 data, the burden that these changes has placed on central and hospital cancer registries, and other factors, the High Level Strategic Group voted not to implement any changes to data collection requirements or the data exchange layout in 2020.

This means that NAACCR Data Standards and Data Dictionary, Volume II, Version 18 will remain in effect through December 31, 2020.

It is our hope that the decision to postpone any further changes until 2021 or later will allow the registry community to focus on the ongoing implementation challenges and the urgent backlog in collection and processing of 2018 cases.

2019 AND 2020

Improved Clarity and Improved Performance
Make - Things - Better



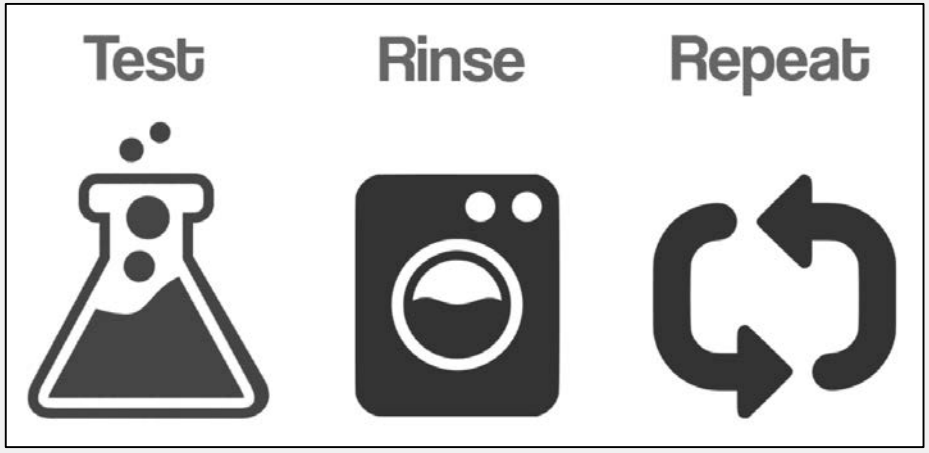
No Change

No Change

Manuals, Instructions, Coding, Edits and Training
More Experience and Improved Feedback

2019 AND 2020

The High Level Strategic Group includes leadership from the ACoS Cancer Programs, NCRA, NPCR, and SEER who meet and discuss potential changes and new requirements in cancer surveillance data collection and to assess the impact of any major changes on data collection staff (registrars) and state central cancer registries before approving any major changes.



FOR FCDS THIS TIME PERIOD IS "CALM BEFORE THE STORM"

- Eventually, FCDS will receive these delayed150,000 cases for 2018. We anticipate receiving them in larger amounts over a shorter period of time than we are used to…and we anticipate that after FCDS Staff process, edit, correct, un-duplicate, force, consolidate, follow-back, and QC the data; we will find areas that need attention and training.
- FCDS anticipates our registries will still be 'late' to abstract and submit cases for 2019 admissions and diagnoses. But, we will get a little closer than for 2018.
- By 2020, we hope most abstracting will be a little more realistically up-to-date.
- 2018-2019 National Cancer Statistics will also be affected. So, what you do and what we do at FCDS and across the country following the 2018 year of major changes is causing ripple effect…until such time as we can all get back on schedule.
- FCDS. DOH and CDC will all be monitoring timelines and data quality more so than ever in an effort to keep track of what is and is not reasonable to ask of registries and registrars in Florida and elsewhere.
- But, we all should expect another big wave of change in 2021. It is already in the works.

2021 – ALL BETS ARE OFF…

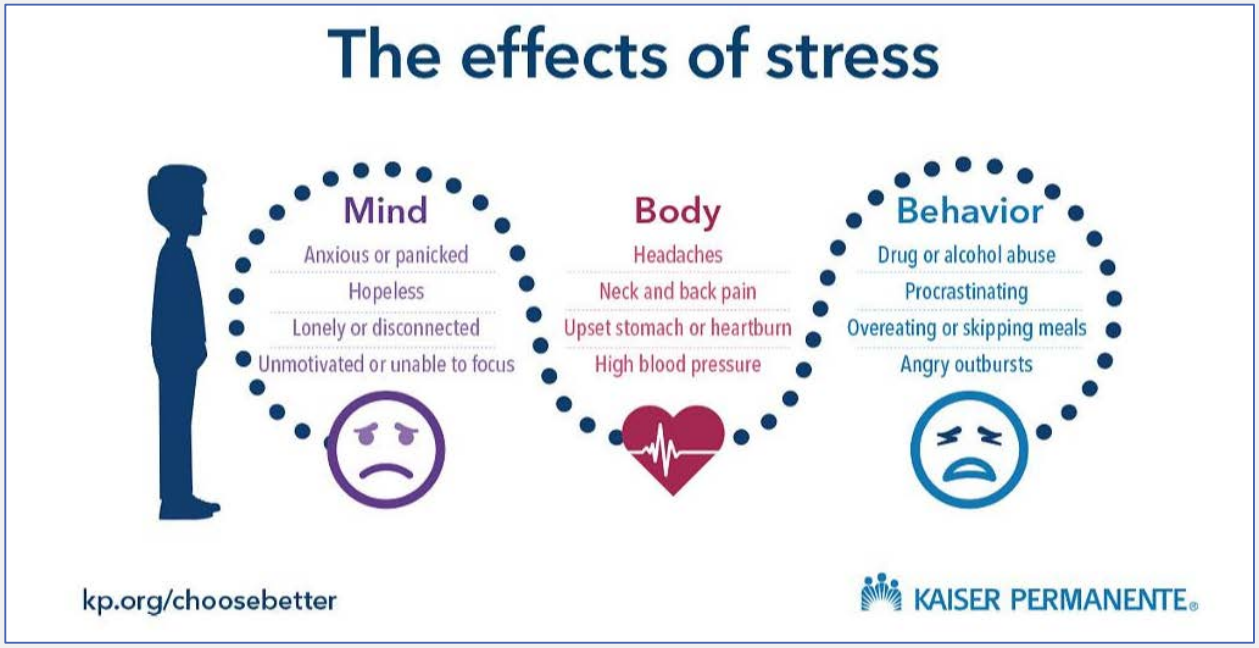
More Data Requirements – NPCR/SEER/CoC
More SSDIs – Changes to Solid Tumor Rules
New ICD-O-3 Updates & New Staging Requirements

New Research to Add New Requirements in Diagnostics (Imaging and Histology), Biomolecular Genetics, Lab Tests, Anti-Neoplastic Agents, etc.

CHANGE SATURATION

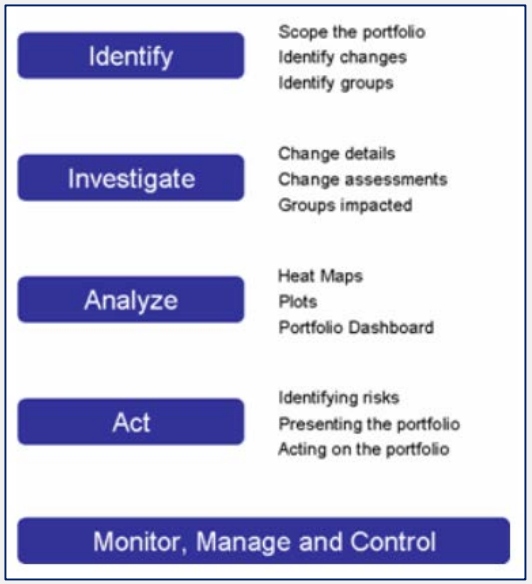
- Change Saturation occurs when there is so much change going on in a field or set of projects/standards that negatively impacts individuals and your organization…compounding the effects of 'change disruption' – it's real.
- Change Saturation most often occurs because no one contact in the organization(s) keeps a "portfolio" view of all the change efforts underway.
- When a project team focuses exclusively on their own set of changes, they do not see how their efforts collide with other changes underway. ICD-O-3, MP/H Rules, Staging, SSDI's, EDITS, Tumor Data Consolidation, etc.
- This is how and why our standard setting organizations (SEER, CoC, AJCC, NAACCR) got so far behind and then had to go back & revise 2018 'stuff'.
- Change Saturation has CONSEQUENCES…
  - Individuals – apathy, frustration, stress, fatigue, burnout, confusion, skepticism, cynicism, lack of productivity, and disengagement with more resistance to change.
  - Projects – delay/failure in product completion and availability (manuals, instructions, software, edits, training) and disharmony with products and projects with interwoven requirements needed to work.
  - Organization – turnover, decline in productivity, increased absenteeism, loss of focus and negative morale – requires management of entire portfolio of change

CHANGE SATURATION



RECOMMENDATIONS SETTING PRIORITIES - MANAGING BACKLOGS - MONITORING RESULTS

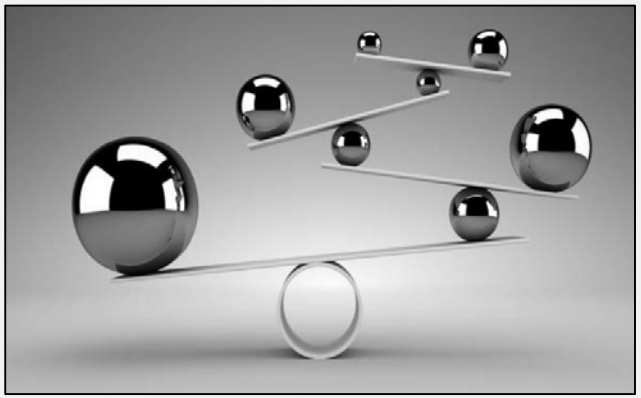
- Keep Administration/Managers Apprised of Current Status
- Set Facility Abstracting Priorities by Year/Month of Service
- Congratulate Your Staff for Every Month Completed !!!
- CAUTION: Contract Abstractors & Interim Staffing Services



- DO NOT Set Abstracting Priorities by Cancer Site or Class of Case or RQRS Requirements for Rapid Reporting !!
- Do Not Prioritize Analytic Cases Over Non-Analytic Cases
- DO NOT Simply Default the SSDIs – they are important!!

- DO Verify Casefinding Lists to Avoid Problems with AHCA
- DO Track Data Quality along with Abstract "Production"

RECOMMENDATIONS SETTING PRIORITIES - MANAGING BACKLOGS - MONITORING RESULTS



- Work Extra Hours
- Track Your Progress
- Maintain Realistic Goals
- Don't Get Distracted – Focus
- Batch Similar Tasks into Groups
- Try Not to Do the Same Thing All Day
- Recognize Burnout and Deal with it Smartly
- Don't Answer Your Phone Every Time It Rings
- Know Your Priorities & Balance Them to Other Tasks
- Break Down Larger Tasks Into Small Tasks When You Can
- Check Email Periodically – Not Every Time an Email Arrives
- Stay Organized - Access to Manuals & Computer Desktop
- Utilize Available Resources Including FCDS Staff & Peers
- Don't Get Stuck on Things That Create Barrier to Completion

OPEN SESSION REMINDERS

- FCDS will be taking detailed notes on these sessions.
- Please Use the Mic and Speak Clearly - One at a Time
- Provide your name/facility so note-taker(s) can write down all Comments, Concerns, Recommendations, Limitations and Failures so we can document them clearly for these sessions.
- Please provide the reasoning behind comments, questions, concerns, what has worked/not worked in your registry, etc.
- Let your voices be heard!!

QUESTIONS

Dunbar, United Kingdom – The Art of Balance