

BETTER COLLABORATIONS FOR CHANGES

HIGH-LEVEL STRATEGIC GROUP (HLSG)

&

MID-LEVEL TACTICAL GROUP (MLTG)

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2019 NPCR Program Review Meeting
4/25/2019

CANCER SURVEILLANCE COMMUNITY —

Always Striving to Do Better



WHAT WE ARE EXPERIENCING -





HIGH-LEVEL STRATEGIC GROUP (HLSG) & MID-LEVEL TACTICAL GROUP (MLTG)

- NAACCR convened two groups, each with 12 voting members
 - HLSG: meet quarterly
 - MLTG: meet monthly
- The two groups consist of representatives from funding agencies and standard setting organizations
 - ACoS/AJCC, ACoS/NCDB, CCCR (Canada), CDC NPCR, NAACCR, NCI SEER, and NCRA

PRIMARY PURPOSES OF HLSCG

- **Ensure high-level coordination and communication** among all cancer surveillance organizations regarding the development and implementation of major changes in standards and procedures.
- **Facilitate communications and collaboration** between the cancer registry/surveillance leadership community and organizational leadership of represented clinical organizations.

PRIMARY PURPOSES OF MLTG

- **Forecast changes** to cancer surveillance collections standards, **evaluate needs** to adapt to changes of oncology practice, and **prepare** an annual report with **recommendations** of new standards (or changes to current standards) to be adopted (or rejected) by the HLSG.
- **Plan for the development of technical standards/specifications** for changes approved by the HLSG.
- **Coordinate the implementation** of changes approved by the HLSG that also completed the development phase.
- **Identify gaps** in resources needed to accomplish development and implementation initiatives and (if appropriate) make recommendations to HLSG for allocation of additional resources.

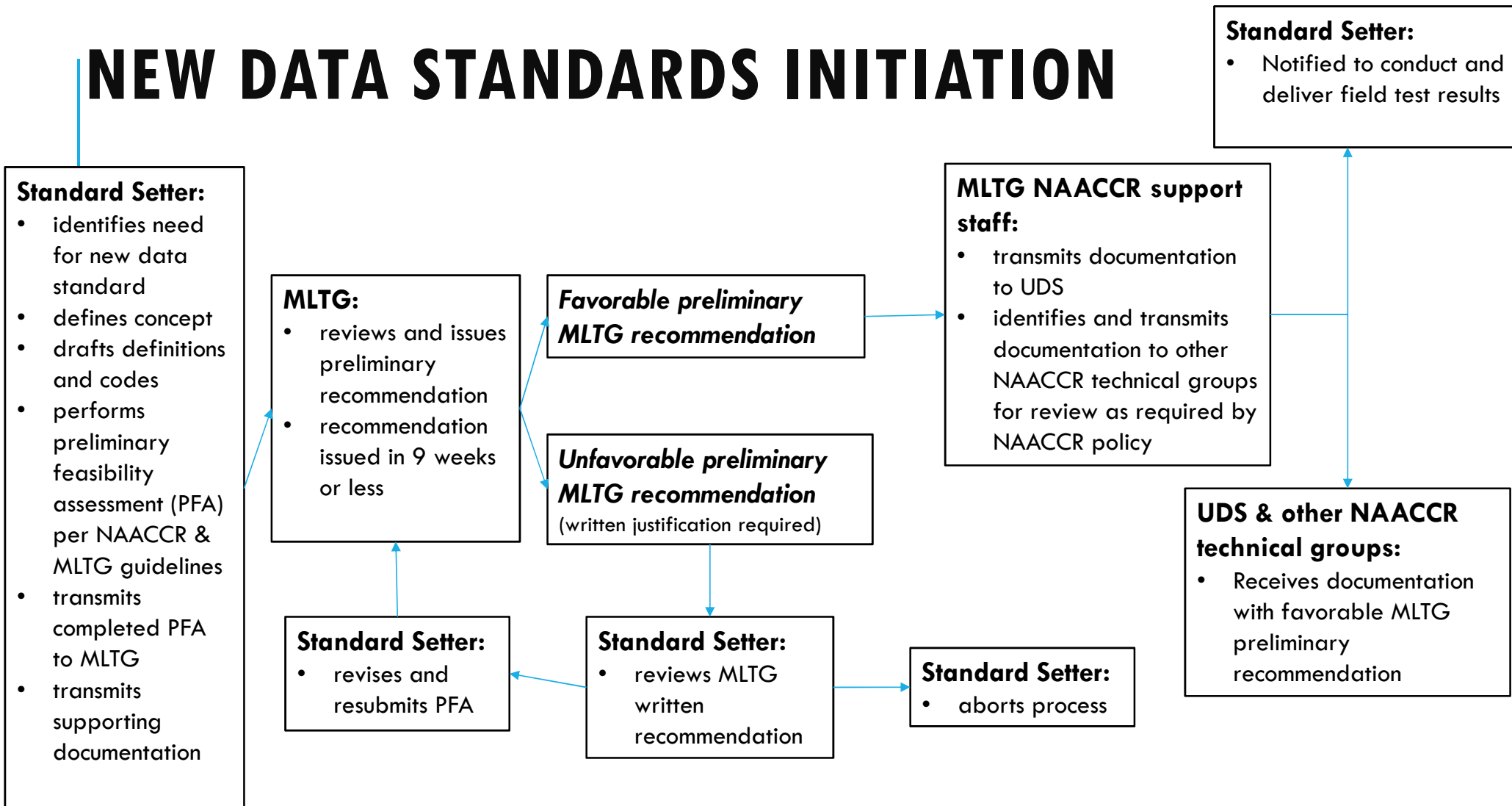
ACTIVITIES SUMMARY FROM HLSG & MLTG

1. Procedures and timeline for new data items
2. Registry readiness for 2018 data changes
3. Requested changes for 2020 implementation
4. Additional changes for 2021-2024

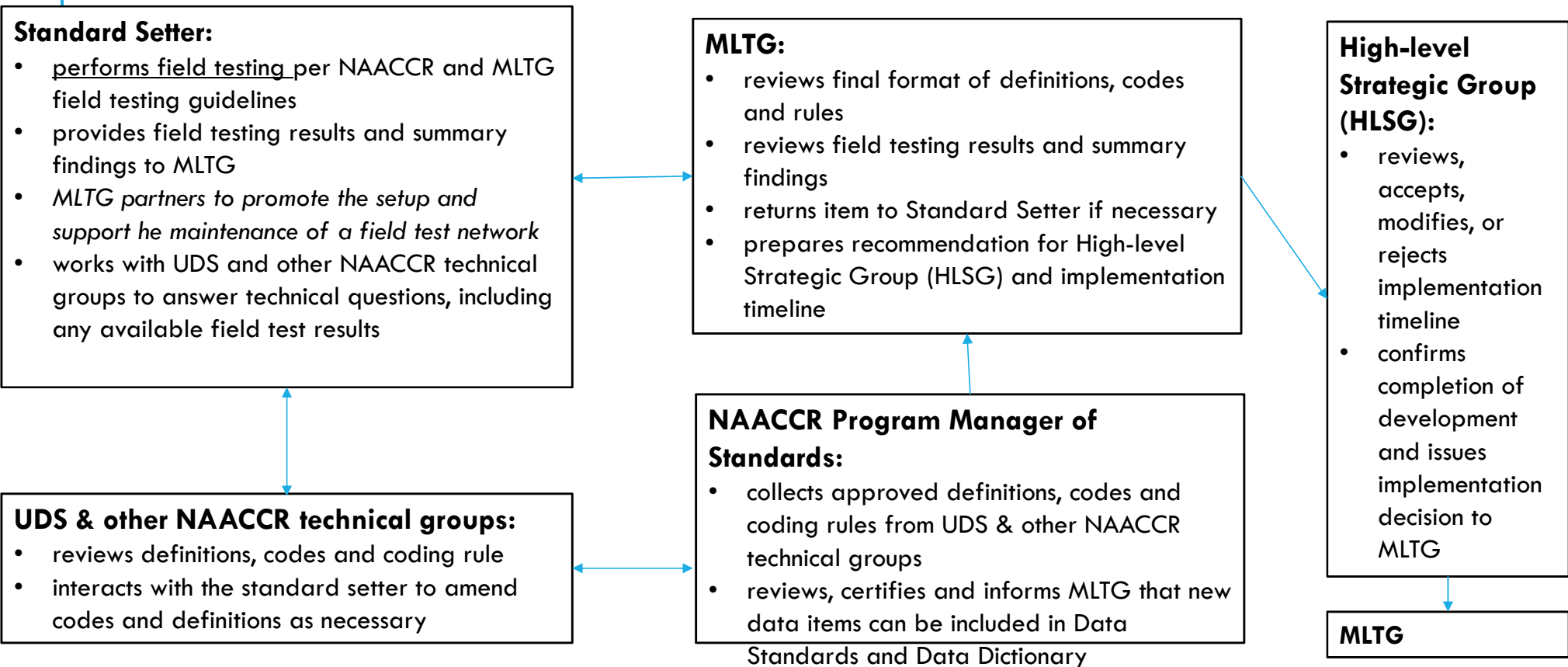
ACTIVITY 1

PROCEDURES AND TIMELINE FOR NEW DATA ITEMS

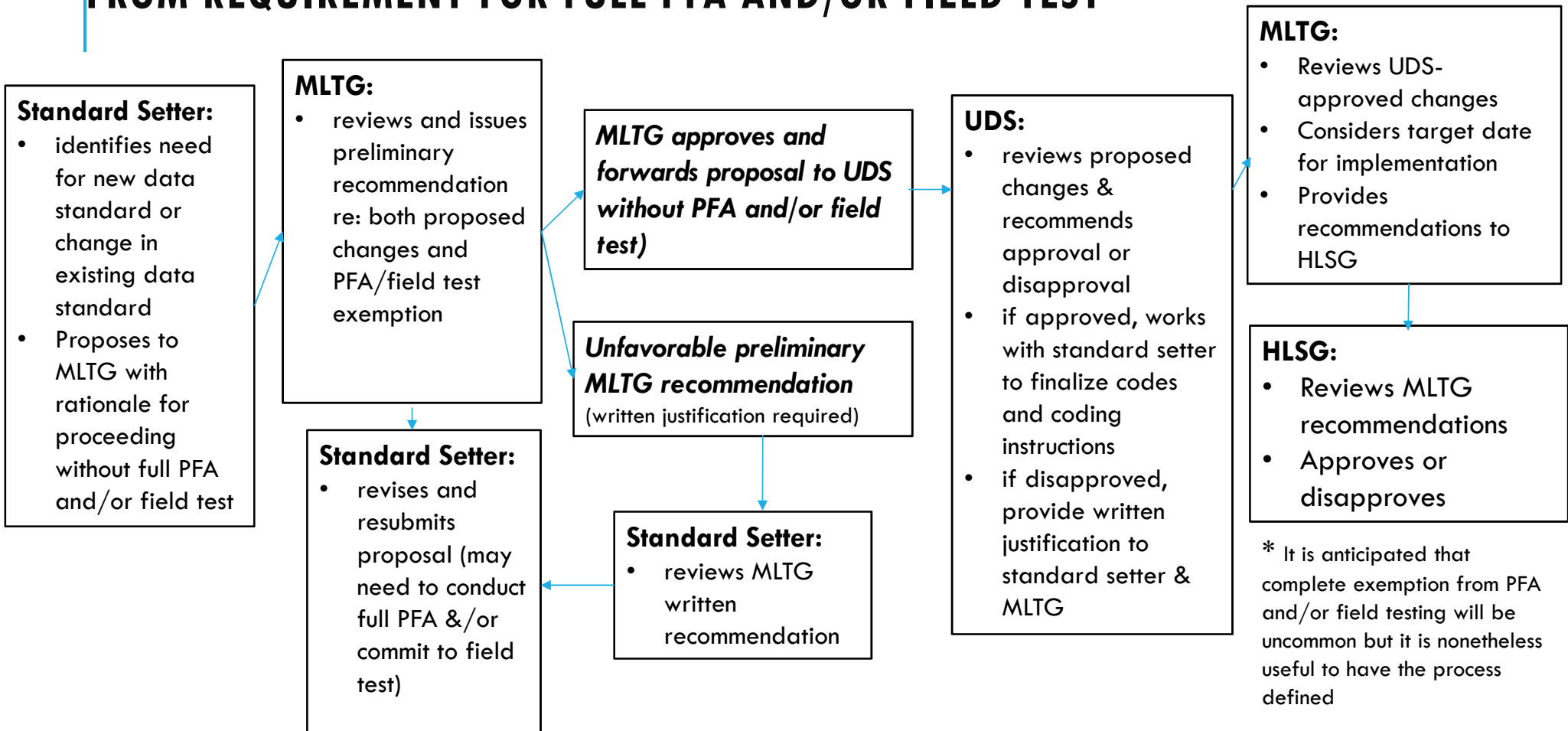
NEW DATA STANDARDS INITIATION



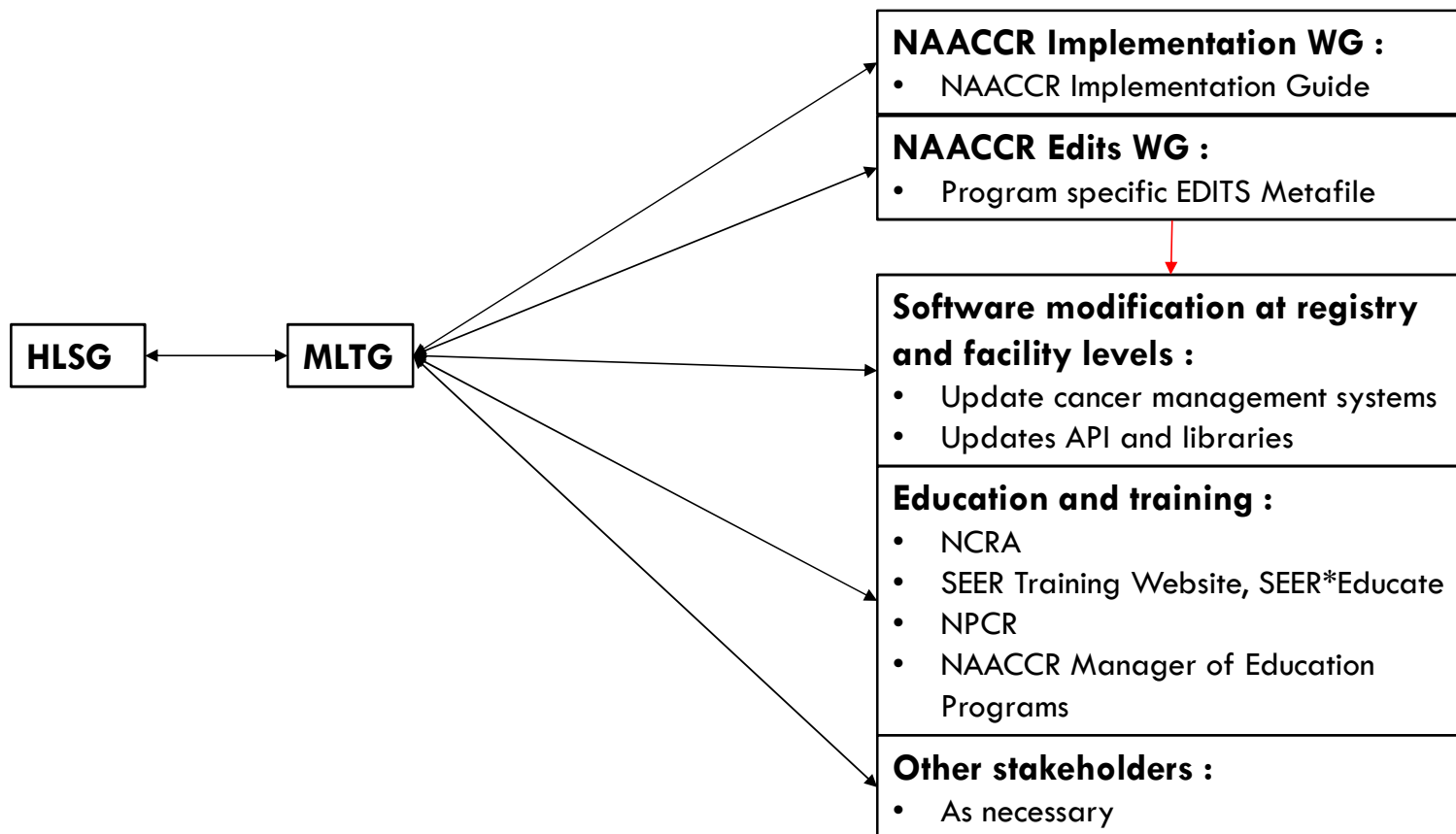
NAACCR TECHNICAL REVIEW & FIELD TESTING



ALTERNATE PROCESS FOR NEW DATA STANDARD OR CHANGE PROPOSED BY STANDARD SETTER WITH REQUEST FOR EXEMPTION FROM REQUIREMENT FOR FULL PFA AND/OR FIELD TEST*



IMPLEMENTATION PROCESS



Draft process and timeline for development and implementation of new SSDI's for 2021 (target completion by August 1, 2020)

February 2019	March 2019	April 2019	May 2019	June 2019	August 2019	September 2019	October 2019	November 2019	December 2019	January 2020	February 2020	March 2020	April 2020	May 2020	June 2020	July 2020
Draft data items and codes reviewed by SSDI																
	Complete plans for feasibility data collection	Feasibility data collection & review		SSDI Approval	MLTG Approval	UDS Comments										
		Develop plans for field test				Field test data collection and review. Finalize codes and coding instructions.			Final UDS review	Final MLTG Review	SLST approval	NAACCR Processes for 2021 Implementation				
Preliminary review of codes and feasibility plan by MLTG		Periodic informational updates to MLTG on field test plan and progress							MLTG and NAACCR evaluate new Change Management; propose changes as needed							

SUMMARY 1: PROCEDURES AND TIMELINE FOR NEW DATA ITEMS

- **Feasibility study** required for each new data item before implementation
- Estimated minimal **9-12 months** before implementation. Time includes:
 - Plan and technical development
 - Feasibility study
 - Review and approval
- At least **6 months** of implementation. Activities includes:
 - Guidelines development
 - Edits
 - Education and Training
 - Central Registry level software modification, test and update
 - Vendor (facilities) level software test and update

ACTIVITY 2

REGISTRY READINESS FOR 2018 DATA CHANGES

Example 1 of 2018 Readiness Survey Result:

- How many 2018 cases have you processed so far (by 3/1/2019)?
(as a percentage of expected cases)

2018 cases processed	Number of registries
0%	24
0.05-5%	13
5-12%	5
59%	1
70%	1

Example 2 of 2018 Readiness Survey Result:

- Has your central registry finalized the v18 Edits Metafile for distribution to reporting facility software vendors (by 3/1/2019)?

	Yes	No	Don't know/ didn't answer
SEER*DMS	8	1	1
Registry Plus	7	8	0
Rocky Mountain	2	6	1
In-house	3	4	0
Other	0	3	0
TOTAL	15	22	2

ADVERSE IMPACTS OF THE DELAY 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

SUMMARY 2: 2018 REGISTRY READINESS

- Overall substantial delays in 2018 data collection
- Identified the need to make distinction between NAACCR edits metafiles and state-specific edit sets
 - Plan for time necessary to develop state-specific edit sets
- Ensure sufficient development time for software updates and testing at multiple levels (API primary developers, CCRs, and facility vendors)
- Training focused on 2018 changes still an issue, in particular for solid tumor rules

ACTIVITY 3

REQUESTED CHANGES FOR 2020 IMPLEMENTATION

CHANGES PROPOSED FOR 2020

1) **Addition of new yc data items**

- Clinical post-neoadjuvant data items by AJCC

2) **Full implementation of XML transmission format**

- Replace data exchange fixed column format for Volume II, V20.

3) **SSDI changes**

- Updates/clarifications on existing 14 items by SEER and SSDI workgroup

4) **Radiation RX modality Phase I, II, and III**

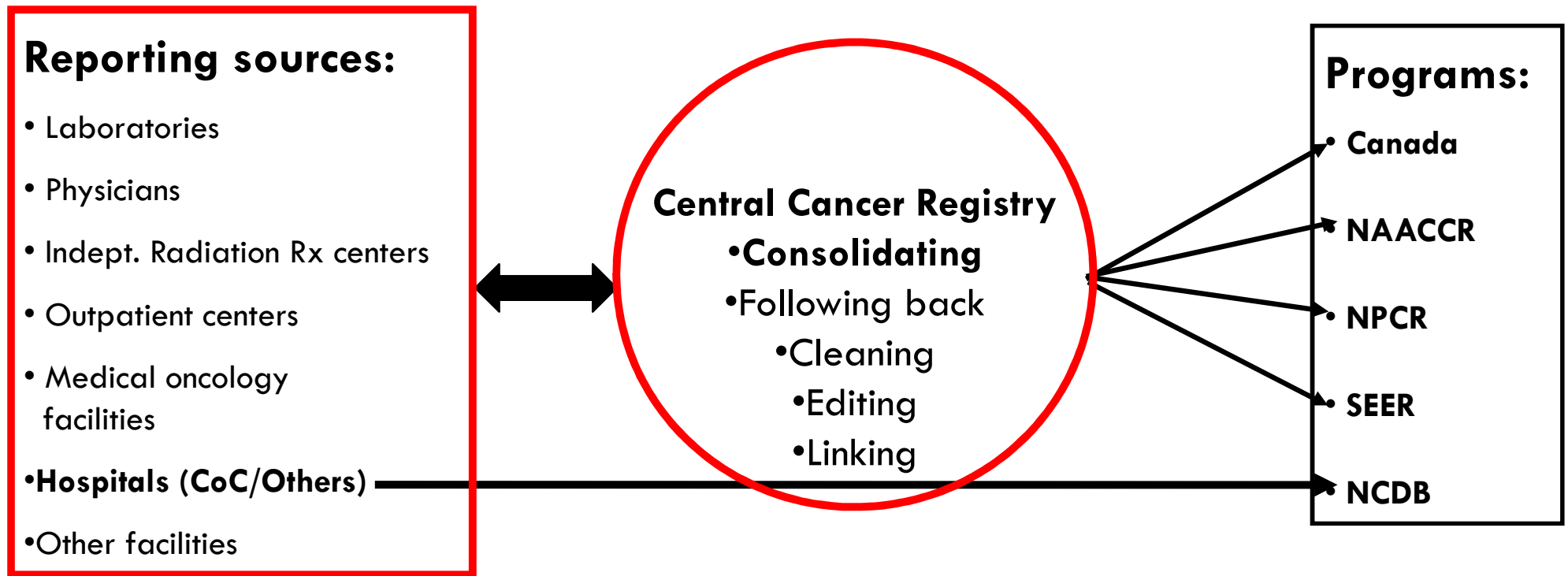
- Add code “98 = Radiation RX administered but RX modality is not specified or unknown”, modify code 99 to “Unknown if radiation RX administered” by AJCC.

POTENTIAL IMPACTS OF PROPOSED CHANGES

	Yc items	XML	SSDIs	Radiation RX Modality items
NAACCR Volume II	Moderate	Minimal	Minimal	Minimal
NAACCR Edits Metafile	Minimal	Minimal to edits; additional tools or modifications needed to existing programs	Minimal	Minimal
Software (Note: Any software update that requires database/table modification or conversion is considered as a major change)				
Software modification for update	Major/Moderate	Major/Moderate	Minimal	Moderate** /Minimal
Central registry level testing and production	Major*	Major/Moderate	Moderate	Moderate
Facility level testing and production	Major	Major	Major	Major
Education & training	Moderate	Moderate	Minimal	Minimal

* Applied to registries which will continually collect TNM. ** Potentially conversion of existing radiation data items

POTENTIAL IMPACTS ON 2018 CANCER DATA COLLECTION AND REPORTS



SUMMARY 3: DECISION ON 2020 CHANGES BY HLSG

- ✓ All of the required changes are important.
- ✓ No changes in 2020.
- ✓ Postpone any further changes until 2021 or later.

ACTIVITY 4

ADDITIONAL CHANGES FOR 2021-2024

PROJECTS UNDER CONSIDERATION FOR DEVELOPMENT & IMPLEMENTATION 2021-2024

- 4 proposed 2020 changes
- Release of the Solid Tumor Database and update of Hematopoietic Database
- Additional data on response to neoadjuvant RX and new SSDIs
- New Collection Feasibility Assessment Framework (NAACCR, NCI, CDC, NCRA)
- New SEER Recodes to improve data usability (histology, EOD, SSF/SSDI)
- Revamping Rapid Cancer Reporting System (CoC NCDB)

PROJECTS UNDER CONSIDERATION FOR DEVELOPMENT & IMPLEMENTATION 2021-2024 (CON'T)

- ICD-O-3.2 expected to be released in April 2019
- 2-4 WHO Classification of Tumours Monographs (Blue Books) are expected to be published between 4/2019 and 6/2020
- ICD-11/ICD-O-4
- Capture of granular RX data/industry standardized coding for systemic RX
- Changes to transmission timelines (NAACCR)
- Interstate Data Exchanges (NAACCR)
- New & Emerging Data Sources (NAACCR)

Better Collaborations for Changes



NPCR & STATE COLLABORATION

How can we work together?

- Mechanisms for state input

How can we better plan for changes?

- Structures or processes
- Communication
- Plan development

NPCR & STATE COLLABORATION

Advocate for states to speak out

- Challenges/Barriers
- Share strategies that work
- Alerts to upcoming potential problems

THANKS YOU!
QUESTIONS AND COMMENTS?

