

Cancer Reporting in California

California Cancer Reporting System Standards, Volume I: Abstracting and Coding Procedures

Twenty-Fifth Edition

Version 1.0, May 2025

Prepared By: California Cancer Registry Cancer Informatics and IT Systems Unit

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Preface to the Twenty-Fifth Edition

The staff of the Cancer Informatics and IT Systems Unit of the California Cancer Registry (CCR) present the twenty-fifth edition of Cancer Reporting in California: Abstracting and Coding Procedures, Volume I, dated May 2025.

Over the past several years, the CCR has had several inquiries asking why Volume I is needed, when we would frequently use Standard Setter Manuals as the reference citation. Additionally, it was felt the information was redundant, a duplication of efforts of the Standard Setters, and was not efficient or effective. While much of Volume I is in alignment with national standard documents, it was developed prior to most national standards manuals. The CCR examined how we could reduce instruction misinterpretations between Volume I and Standard Setter Manuals. Therefore, for 2025, we offer Volume I in a hybrid design, with links to the National Standard Setter Manuals we source. Additionally, any California-specific data item instructions will remain within the Volume as the responsibility of the CCR for maintenance as needed. We encourage registrars to review the new "Using Volume I" section. This section will provide guidance on using the revised volume, as well as suggestions for referencing the Standard Setter Manuals. We believe this approach offers a nice balance and makes it easier for registrars by eliminating possible misinterpretations.

The changes for 2025 include two new SSDIs: PD-L1, PDLD, and a new Pediatric Data Collection System (PDCS), which includes 25 new pediatric specific data items: 13 coded, 12 calculated. Revised items include: SSDIs: BRAF Mutational Analysis within Colon and Rectum: code 3 was added to capture abnormal (mutated)/detected, *KIAA1549: BRAF* gene fusion. Other revisions: Format changes for the Path Date Spec Collect 1-5 data items from date data type to dateTime datatype. There are 30 retired data items in 2025, listed in the <u>NAACCR 2025 Implementation</u> <u>Guidelines and Recommendations</u>. There are **no** ICD-O-3 updates for 2025. Please continue to use the <u>2024 revisions to ICD-O-3.2</u>. The CCR is adopting the 2025 Standard Setter revisions based on the Implementation Guide linked above.

Please refer to the "Cancer Reporting in California: Abstracting and Coding Procedures, California Cancer Reporting System Standards, Volume I, Changes and Clarifications - 25th Edition, May 2025", for a detailed summary of the revision or clarification to Volume I in the 2025 version which is posted to the CCR web site.

We want to acknowledge the Analysts from the Cancer Informatics and IT Systems Unit, California Cancer Reporting and Epidemiologic Surveillance (CalCARES) Program, for this year's review, reduction, and revision of Volume I. We would also like to thank the Greater Bay area Cancer Registry, the Cancer Registry of Greater California, and the Los Angeles County Cancer Surveillance Program, for your continued contributions to the success of Volume I.

Reporting facilities in California should direct any corrections, comments, and suggestions regarding this document to their regional registry. The regional registry will send/forward this information to the CCR. If individuals or facilities that are not part of the California reporting system need copies of Volume I, they may download the PDF from the California Cancer Registry website.

Thank you for your continued commitment to ensure that the CCR data is of the highest quality. The data you provide remains the cornerstone of the California Cancer Registry.

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Using Volume I

This section is to aid in the understanding of the reduction of Volume I. Specifically, where coding instructions refer to a Standard Setter Manual, or where we have moved, combined, or eliminated previous coding instructions/guidelines.

CCR Specific Guidelines:

- Use the following table as a quick-look guide for revisions made during the reduction, restructure, and 2025 data change revisions of Volume I.
- When referring to a Standard Setter Manual, the following actions occurred.
 - Added Standard setter "Source" to be used for coding instructions and guidelines.
 - Coding instructions were added, revised or removed.
 - Kept or created CCR Specific Guidelines and/or CCR Specific Coding Instructions.
 - Kept Standard Setter Difference sections, where the CCR differs from the Standard Setter or we go with one over the other (i.e. CCR follows SEER over STORE or vs versa).
- Use the find function (CTR+F) to search within the Standard Setter Manuals to find specific data items or topics.
- Any sections or items not listed in the table were not updated.

Acronym and links for manuals listed in table below:

- AJCC AJCC Cancer Staging Manual
- AJCC v9 Version 9 Cancer Staging System
- CA PathCHART <u>Cancer Pathology Coding Histology and Registration Terminology</u> (<u>Cancer PathCHART</u>)
- CASEFINDING LISTS <u>ICD-10-CM Casefinding List</u>
- CCR <u>California Cancer Registry</u>
 - **VOL I** <u>*CCR Volume I, Abstracting and Coding Procedures*</u>
 - Appendix A Patient Notification of Reportable Neoplasm
 - <u>Appendix B Codes for California Counties</u>
 - Appendix C Residency of Military Personnel
 - <u>Appendix D Spanish Surnames</u>
 - <u>Appendix E Codes for Religions</u>
 - <u>Appendix F Site-Specific Data Items (SSDIs)</u>
 - <u>Appendix G Data Alerts and Data Memos</u>
 - Appendix H Q-Tips
 - <u>Appendix I Coding Resources</u>
 - o VOL II <u>CCR Volume II, Standards for Automated Reporting</u>
- EOD Extent of Disease 2018 General Instructions
- GRADE <u>Grade Coding Instructions and Tables</u>
- HEME <u>Hematopoietic and Lymphoid Neoplasm Database and Hematopoietic & Lymphoid</u> <u>Neoplasm Coding Manual</u>

- NAACCR Abbreviations and Acronyms <u>NAACCR Abbreviations and Acronyms</u>
- PDCS <u>Pediatric Data Collection System and Staging Manual</u>
- PDCS SEER*RSA <u>Pediatric Staging on SEER*RSA</u>
- SEER*RSA <u>SEER*RSA Cancer Schema List</u>
- SPM SEER Program Coding and Staging Manual
 - <u>SPM-Appendix A County Codes</u>
 - <u>SPM-Appendix B Country and State Codes</u>
 - <u>SPM-Appendix C Site Specific Coding Modules</u>
 - o <u>SPM-Appendix D Race and Nationality Descriptions</u>
 - SPM-Appendix E Reportable and Non-reportable Examples
- SSDI Site-Specific Data Item (SSDI) Manual
- SS2018 <u>Summary Stage 2018 Manual</u>
- STORE Standards for Oncology Registry Entry (STORE)Manual
- STR <u>Solid Tumor Rules</u>

Table of Changes for Volume I Restructure / 2025 Data Changes

OLD Volume I Section #	OLD Volume I Topic	Action
N/A	Preface	Revised for Restructure / 2025 Data Changes
NEW	Using Volume I	Added section no number: Using Vol I (above Part I. Introduction)
Part I.	Introduction	N/A
I.1.3	State Cancer Reporting Requirements	Updated link to Renumbered/Renamed Appendix A - Patient Notification of Reportable Neoplasm
I.1.4	Confidentiality	Updated link to Renumbered/Renamed Appendix A - Patient Notification of Reportable Neoplasm
I.1.5	Casefinding	Refer to ICD-10-CM Casefinding List
I.1.5.2.2	Casefinding - Health Information Management (HIM)/Medical Record	Refer to ICD-10-CM Casefinding List
I.1.6	Reporting	Renamed to Reporting in California; Combined I.1.6.1- 2 into this section
I.1.6.1	Definition of Cancer	Combined into I.1.6; Removed from Vol I
I.1.6.2	Abstracting Cancer Data	Combined into I.1.6; Removed from Vol I
I.1.6.3	Entering Dates	Renumbered to I.1.6.1
I.1.6.4	Date Format	Removed from Vol I; Covered in SPM
I.1.7	Reporting by Non-Hospital Treatment Centers	Renumbered to I.1.6.2
I.1.8	Cases Diagnosed and Treated Elsewhere	Renumbered to I.1.6.3; Added guideline

Part II.	Reportable Neopasms	Added Guidelines; Links to Appendices
П.1	CCR Reportability Guide - Reportable	Revised; Refer to SPM and <i>SPM-Appendix E -</i> <i>Reportable and Non-reportable Examples</i> ; Kept Standard Setter Differences
П.1.1	CCR Reportability Guide - Non- Reportable or Historically Reportable	Renumbered to II.2
II.2	Determining Reportability	Combined into I.1.6; Removed from Vol I
II.2.1	Identifying the Primary Neoplasm and Single or Multiple Tumors	Combined into I.1.6; Removed from Vol I
II.2.2	Ambiguous Diagnostic Reportable Terms	Combined into I.1.6; Referenced in II.1; Removed from Vol I
II.2.3	Pathology and Consultation Only Cases	Combined into I.1.6; Removed from Vol I
II.2.4	Hematopoietic and Lymphoid Neoplasm	Combined into I.1.6; Removed from Vol I
II.2.5	Benign/Borderline Brain and CNS Tumors	Combined into I.1.6; Removed from Vol I
II.2.5.1	Date of Diagnosis for Benign/Borderline Brain and CNS Tumors	Removed from Vol I; Covered in SPM
II.2.5.2	Malignant Transformation - Brain and CNS Tumors	Removed from Vol I; Covered in SPM
II.2.5.3	WHO Grade - Benign/Borderline Brain and CNS Tumors	Removed from Vol I; Covered in SPM
II.3	Abstracting - Accession and Sequence Number	Moved to part III; New # is III.3.2; Combined with II.3.2-3; Ref to STORE
II.3.1	Year First Seen	Moved to Part III. New # is III.3.1
II.3.2	Accession Number	Moved to Part III. New # is III.3.2; Combined with II.3.2-3; Ref to STORE
II.3.3	Sequence Number	Moved to Part III. New # is III.3.2; Combined with II.3.2-3; Ref to STORE
II.3.4	Other Tumors/Primaries	Combined into IV.3; Removed from Vol I
Part III.	Identification	Added Guidelines; Added links to Appendices
III.1.3	CoC Accredited Flag	Refer to SPM
III.2.1	Name	Refer to SPM; Kept CCR Specific Coding Instructions; Removed subsections III.2.1.1-4
III.2.5	Phone Number (Patient)	Refer to SPM
III.2.6	Address at Diagnosis	Refer to SPM; Kept Standard Setter Difference; Added link to Appendix C - Residency of Military Personnel
III.2.6.1	Number and Street at DX	Removed from Vol I; Covered in SPM
III.2.6.2	City at DX	Removed from Vol I; Covered in SPM

III.2.6.3	State at DX	Removed from Vol I; Covered in SPM
III.2.6.4	ZIP at DX	Removed from Vol I; Covered in SPM
III.2.6.5	County at DX	Removed from Vol I; Covered in SPM
III.2.6.6	Country at DX	Removed from Vol I; Covered in SPM
III.2.7	Marital Status	Refer to SPM
III.2.9	Religion	Updated link to renumbered <i>Appendix E - Codes for</i> <i>Religions</i>
III.2.10	Race and Ethnicity	Revised; Refer to SPM; Updated link to SPM-Appendix D - Race and Nationality Descriptions
III.2.10.1	Codes for Race Data Item	Highlighted CCR Specific Code
III.2.10.2	Spanish/Hispanic Origin	Refer to SPM; Added CCR Guideline; Added link to Appendix D - Spanish Surnames
III.2.11	Date of Birth	Refer to SPM
III.2.12	Age at Diagnosis	Refer to SPM
III.2.13	Birthplace - Country	Refer to SPM and SPM-Appendix B - Country and State Codes
III.2.13.1	Birthplace - State	Refer to SPM and SPM-Appendix B - Country and State Codes
III.2.15	No Patient Contact Flag	Refer to SPM
III.2.17	Weight	Moved Guidelines above Coding Instructions
III.2.18.2	Tobacco Use Smoking Status	Refer to SPM
III.2.19	Source Comorbidity	Renumbered to III.3.14.2
III.3.1	Date of First Contact	Renumbered to III.3.3; Refer to STORE
III.3.2	Dates of Inpatient Admission and Inpatient Discharge	Renumbered to III.3.4
III.3.3	Date of Diagnosis	Renumbered to III.3.5; Refer to SPM
III.3.3.1	Vague Dates	Removed from Vol I; Covered in SPM
III.3.3.2	Approximation	Removed from Vol I; Covered in SPM
III.3.4	Place of Diagnosis	Renumbered to III.3.6
III.3.5	Class of Case	Renumbered to III.3.7; Updated link name
III.3.6	Type of Reporting Source	Renumbered to III.3.8
III.3.7	Type of Admission	Renumbered to III.3.9; Updated link name
III.3.8	Casefinding Source	Renumbered to III.3.10
III.3.9	Payment Source (Primary and Secondary) and Payment Source Text	Renumbered to III.3.11; Revised; Kept Standard Setter Difference; Highlighted CCR specific codes
III.3.10	Reporting Facility Referred From	Renumbered/Renamed to III.3.12; Reporting Facility Referred from and Referred To
III.3.11	Reporting Facility Referred To	Combined into new III.3.12; Removed from Vol I

III.3.12	Physicians	Renumbered to III.3.13
III.3.12.1	Physician License Numbers	Renumbered to III.3.13.1
III.3.12.2	Entering Physician NPI Codes	Renumbered to III.3.13.2; Combined Appendix P into this section
III.3.13	Secondary Diagnosis 1-10	Combined into III.3.14; Removed from Vol I
III.3.14	Comorbidities and Complications	Renamed to Comorbidities and Complications/Secondary Diagnosis; Combined Secondary Diagnosis into this section; Refer to STORE
III.3.15	ICD Revision - Comorbidities and Complications	Renumbered to III.3.14.1; Refer to STORE
III.3.16	Discovered by Screening	Renumbered to III.3.15
Part IV.	Diagnostic Procedures	Renamed to Text Documentation; Added Guidelines; Added links to Appendices
IV.1	Text - Diagnostic Procedures Performed	Incorporated into other text workup sections in Part IV; Section removed from Vol I
NEW	General Guidelines for Text in the Abstract	Added section numbered IV.1; New section for General Guidelines for Text in the Abstract; Incorporated part of Appendix T in this section
NEW	Best Practices for Text Fields	Added section numbered IV.2; New section for Best Practices for Text Fields; Incorporated part of Appendix T in this section
IV.1.1	Text - Physical Examination	Renumbered to IV.4; Revised; Incorporated part of Appendix T in this section; Added example
IV.1.2	Text - X-Ray/Scans	Renumbered to IV.5; Incorporated part of Appendix T in this section
IV.1.3	Text - Scopes	Renumbered to IV.6; Revised; Incorporated part of Appendix T in this section
IV.1.4	Text - Laboratory Tests	Renumbered to IV.7; Revised; Incorporated part of Appendix T in this section
IV.1.5	Text - Operative Findings	Renumbered to IV.8; Revised; Incorporated part of Appendix T in this section
IV.1.6	Text - Pathology Findings	Renumbered to IV.9; Revised; Incorporated part of Appendix T in this section
IV.1.6.1	Pathology Report Identifier Data Items	Moved to Part VI: New # is VI.2.5
IV.1.7	Text - Staging	Renumbered to IV.10; Revised; Incorporated part of Appendix T in this section
NEW	Text - First Course of Treatment	Added section numbered IV.12; Incorporated part of Appendix T in this section
NEW	Text - Surgery	Added section numbered IV.12.1; Incorporated part of Appendix T in this section
NEW	Text - Radiation Therapy	Added section numbered IV.12.2; Incorporated part of Appendix T in this section

NEW	Text - Systemic Therapy Fields	Added section numbered IV.12.3; Incorporated part of Appendix T in this section
NEW	Text - Other Therapy	Added section numbered IV.12.4; Incorporated part of Appendix T in this section
NEW	Text - Documenting Neoadjuvant Therapy in text	Added section numbered IV.12.5; Incorporated part of Appendix T in this section
IV.2	Diagnostic Confirmation	Moved to Part V; New # is V.3
Part V.	Tumor Data	Added Guidelines; Added links to Appendices
V.1	Primary Site	Refer to SPM & STR
V.1.1	Identification of Separate Sites	Removed from Vol I; Covered in SEER Manuals
V.1.2	Indefinite and Metastatic Sites	Removed from Vol I; Covered in SEER Manuals
V.1.3	Primary Site - Site-Specific Special Conditions	Removed from Vol I; Covered in SEER Manuals
V.1.4	Uncertain Primary Site	Removed from Vol I; Covered in SEER Manuals
V.2	Laterality	Refer to SPM
V.2.1	Laterality - Paired Sites	Removed from Vol I; Covered in SPM
V.3	ICD-O Morphology - Histology and Behavior	Renumbered to V.4; Revised; Refer to STR, HEME, CA PathCHART, Added link to <i>Appendix H - Q-Tips</i>
V.3.1	Histologic Type	Renumbered to V.4.1; Renamed to Histologic Type ICD-O-3; Refer to STR, HEME
V.3.2	Unspecified Malignancies	Renumbered to V.4.2; Refer to STR
V.3.3	Behavior	Renumbered to V.4.3; Refer to SPM
V.3.3.1	In-Situ Coding	Removed from Vol I; Covered in SEER Manuals
V.3.4	Cancer PathCHART Site- Morphology Combination Standards	Removed from Vol I; Covered in V.4
V.4	Grade and Differentiation	Renumbered to V.5; Refer to Grade
V.4.1	Grade - General Information	Removed from Vol I; Covered in Grade
V.4.1.1	Grade - Clinical	Removed from Vol I; Covered in Grade
V.4.1.2	Grade - Pathological	Removed from Vol I; Covered in Grade
V.4.1.3	Grade - Post Therapy Clin (yc)	Removed from Vol I; Covered in Grade
V.4.1.4	Grade - Post Therapy Path (yp)	Removed from Vol I; Covered in Grade
V.5	Tumor Size	Renumbered to V.6; Refer to SPM
V.5.1	Tumor Size Summary	Removed from Vol I; Covered in SPM
V.6	Mets at Diagnosis Bone, Brain, Liver, Lung, Distant Lymph Nodes, and Other	Renumbered to V.7; Refer to SPM
V.6.1	Mets at Diagnosis - Bone	Removed from Vol I; Covered in SPM
V.6.2	Mets at Diagnosis - Brain	Removed from Vol I; Covered in SPM
V.6.3	Mets at Diagnosis - Liver	Removed from Vol I; Covered in SPM

V.6.4	Mets at Diagnosis - Lung	Removed from Vol I; Covered in SPM
V.6.5	Mets at Diagnosis - Distant Lymph Node(s)	Removed from Vol I; Covered in SPM
V.6.6	Mets at Diagnosis - Other	Removed from Vol I; Covered in SPM
V.7	Lymphovascular Invasion	Renumbered to V.8; Refer to SPM; Kept CCR Specific Coding Instructions
V.8	Terms Indicating In-situ for Staging	Removed from Vol I; Covered in Mult Manuals
V.9	Stage at Diagnosis	Combined V.9.1-V.12.1,V.14-V.15.2 into this section; Added <i>Pediatric Data Collection System and Staging</i> <i>Manual</i> for 2025 Data Changes
V.9.1	Staging Requirements	Combined into V.9; Removed from Vol I
V.10	AJCC TNM Staging	Combined into V.9; Covered in STORE and AJCC; Removed from Vol I
V.10.1	AJCC TNM Staging General Information	Removed from Vol I, Covered in STORE and AJCC
V.10.2	AJCC TNM Edition Number	Removed from Vol I, Covered in STORE and AJCC
V.10.3	AJCC - Ambiguous Terms for Disease Extension	Removed from Vol I, Covered in STORE and AJCC
V.11	Extent of Disease (EOD)	Combined into V.9; Removed from Vol I
V.11.1	EOD General Information	Removed from Vol I; Covered in EOD
V.11.1.1	EOD - Primary Tumor	Removed from Vol I; Covered in EOD
V.11.1.2	EOD - Regional Nodes	Removed from Vol I; Covered in EOD
V.11.1.3	EOD - Mets	Removed from Vol I; Covered in EOD
V.11.2	EOD Prostate Pathological Extension	Removed from Vol I; Covered in EOD
V.11.3	EOD - Ambiguous Terms for Extent of Disease	Combined into V.9; Removed from Vol I
V.12	Site-Specific Data Items (SSDIs)	Combined into V.9; Removed from Vol I
V.12.1	SSDI General Information	Removed from Vol I; Covered in SSDI
V.13	SEER Site-Specific Factor 1	Renumbered to V.10; Refer to SPM
V.14	STandards for Oncology Registry Entry (STORE)	Combined into V.9; Removed from Vol I
V.14.1	STORE General Information	Removed from Vol I; Covered in STORE
V.14.2	STORE - Ambiguous Terms Describing Tumor Spread	Combined into V.9; Removed from Vol I
V.15	Summary Stage 2018 (SS2018)	Combined into V.9; Removed from Vol I
V.15.1	SS2018 General Information	Removed from Vol I; Covered in SS2018
V.15.1.1	SS2018 - In-situ (Code 0)	Removed from Vol I; Covered in SS2018
V.15.1.2	SS2018 - Localized (Code 1)	Removed from Vol I; Covered in SS2018

V.15.1.3	SS2018 - Regional (Codes 2-4)	Removed from Vol I; Covered in SS2018
V.15.1.3.1	SS2018 - Regional by Direct Extension Only (Code 2)	Removed from Vol I; Covered in SS2018
V.15.1.3.2	SS2018 - Regional Lymph Nodes Only (Code 3)	Removed from Vol I; Covered in SS2018
V.15.1.3.3	SS2018 - Regional by BOTH Direct Extension AND Regional Lymph Node(s) Involved (Code 4)	Removed from Vol I; Covered in SS2018
V.15.1.4	SS2018 - Distant Metastasis (Code 7)	Removed from Vol I; Covered in SS2018
V.15.1.5	SS2018 - Benign/Borderline (Code 8)	Removed from Vol I; Covered in SS2018
V.15.1.6	SS2018 - Unknown if Extension or Metastatic (Unstaged, Unknown, or Unspecified) (Code 9)	Removed from Vol I; Covered in SS2018
V.15.2	SS2018 Ambiguous Terms for Disease Extension	Combined into V.9; Removed from Vol I
V.16	Pediatric Stage	Renumbered to V.11, added paragraph explaining this is CCR Specific and should not be confused with PDCS
V.16.1	Pediatric Stage Group	Renumbered to V.11.1
V.16.2	Pediatric Protocols	Renumbered to V.11.2
V.16.3	Staged by - Pediatric Stage	Renumbered to V.11.3
Part VI.	First Course of Treatment	Added Guidelines; Added links to Appendices
VI.1	Definitions and Guidelines - First Course of Treatment	Added CCR Expectations; Added link to Text - First Course of Treatment
VI.1.1	First Course of Treatment - Special Situations	Removed from Vol I; Covered in SPM
VI.1.2	First Course of Treatment - Data Entry	Moved instructions to appropriate treatment sections; Removed from Vol I
VI.1.3	Neoadjuvant Treatment - First Course of Treatment	Renumbered to VI.1.1; Revised; Refer to SPM
VI.1.3.1	Neoadjuvant Therapy	Combined into VI.1.1; Section removed from Vol I
VI.1.3.2	Neoadjuvant Therapy - Clinical Response	Combined into VI.1.1; Section removed from Vol I
VI.1.3.3	Neoadjuvant Therapy - Treatment Effect	Combined into VI.1.1; Section removed from Vol I
VI.2	Surgery Introduction - First Course of Treatment	Added Guidelines; Standard Setter Difference; and link to STORE-Appendix M - Case Studies for Coding Melanoma in STORE
VI.2.1	Treatment Facility Number	Renumbered to VI.1.3; Revised
NEW	Surgery Data Items - Refer to STORE	Added section numbered VI.2.1; Lists surgical data items to refer to STORE; link to STORE-Appendix M - Case Studies for Coding Melanoma in STORE

		Added section numbered VI.2.2; Lists surgical data
NEW	Surgery Data Items - Refer to SPM	Added section numbered V1.2.2, Elsis surgical data items to refer to SPM; link to SPM and STORE- Appendix M - Case Studies for Coding Melanoma in STORE
NEW	CCR Scope of Regional Lymph Node Surgery Tables	Added section numbered VI.2.4; CCR Code Tables kept, augmenting the SPM
VI.2.3	Diagnostic or Staging Procedures	Listed in VI.2.1; Refer to STORE; Removed from Vol I
VI.2.3.1	Date of Diagnostic or Staging Surgical Procedures	Removed from Vol I; Covered in STORE
VI.2.4	Surgery of Primary Site 2023	Listed in VI.2.2; Refer to SPM; Removed from Vol I
VI.2.4.1	Date of Surgery	Removed from Vol I; Covered in SPM
VI.2.4.2	Surgical Margins of the Primary Site	Listed in VI.2.2; Refer to SPM; Removed from Vol I
VI.2.4.3	Macroscopic Evaluation of the Mesorectum	Listed in VI.2.1; Refer to STORE; Removed from Vol I
VI.2.4.4	Breast Reconstruction	Listed in VI.2.1; Refer to STORE; Removed from Vol I
VI.2.5	Sentinel Lymph Node Biopsy	Listed in VI.2.2; Refer to SPM; Kept CCR Guidelines; Removed from Vol I
VI.2.5.1	Date of Sentinel Lymph Node Biopsy	Revised; Renumbered to VI.2.3
VI.2.5.2	Sentinel Lymph Nodes Positive	Listed in VI.2.2; Refer to SPM; Removed from Vol I
VI.2.5.3	Sentinel Lymph Nodes Examined	Listed in VI.2.2; Refer to SPM; Removed from Vol I
VI.2.6	Scope of Regional Lymph Node Surgery	Listed in VI.2.2; Refer to SPM; Kept CCR Guidelines; Removed from Vol I
VI.2.6.1	Date of Regional Lymph Node Dissection	Listed in VI.2.2; Refer to SPM; Removed from Vol I
VI.2.6.2	Regional Lymph Nodes Positive	Listed in VI.2.2; Refer to SPM; Removed from Vol I
VI.2.6.3	Regional Lymph Nodes Examined	Listed in VI.2.2; Refer to SPM; Removed from Vol I
VI.2.7	Special Rules for Counting Lymph Nodes	Listed in VI.2.2; Refer to SPM; Removed from Vol I
VI.2.8	Surgery of Other Regional Sites, Distant Sites, or Distant Lymph Nodes	Removed from Vol I; Covered in SPM
VI.2.9	Surgery of Synchronous Primaries	Listed in VI.2.2; Refer to SPM; Removed from Vol I
VI.2.10	Systemic Therapy with Surgery Sequence	Listed in VI.2.2; Refer to SPM; Removed from Vol I
VI.2.11	Reason for No Surgery of the Primary Site	Listed in VI.2.2; Refer to SPM; Removed from Vol I
VI.3	Radiation Therapy - First Course of Treatment	Refer to STORE and STORE Appendix R
VI.3.2	Date of Radiation Therapy	Removed from Vol I; Covered in STORE

	Radiation Phases I-III General	Listed in VI.3; Refer to <i>STORE-Appendix R</i> ; Removed
VI.3.3	Information	from Vol I
VI.3.3.1	Radiation Primary Treatment Volume - Phases I-III	Listed in VI.3; Refer to <i>STORE-Appendix R</i> ; Removed from Vol I
VI.3.3.2	Radiation to Draining Lymph Nodes - Phases I-III	Listed in VI.3; Refer to <i>STORE-Appendix R</i> ; Removed from Vol I
VI.3.3.3	Radiation Treatment Modality - Phases I-III	Listed in VI.3; Refer to <i>STORE-Appendix R</i> ; Removed from Vol I
VI.3.3.4	Radiation External Beam Planning Technique - Phases I-III	Listed in VI.3; Refer to <i>STORE-Appendix R</i> ; Removed from Vol I
VI.3.3.5	Dose per Fraction - Phases I-III	Listed in VI.3; Refer to <i>STORE-Appendix R</i> ; Removed from Vol I
VI.3.3.6	Number of Fractions - Phases I-III	Listed in VI.3; Refer to <i>STORE-Appendix R</i> ; Removed from Vol I
VI.3.3.7	Total Dose - Individual Phases I- III	Listed in VI.3; Refer to <i>STORE-Appendix R</i> ; Removed from Vol I
VI.3.4	Number of Phases of Rad Treatment to this Volume	Listed in VI.3; Refer to <i>STORE-Appendix R</i> ; Removed from Vol I
VI.3.5	Radiation Total Dose - Phases Combined	Listed in VI.3; Refer to <i>STORE-Appendix R</i> ; Removed from Vol I
VI.3.6	Radiation Sequence with Surgery	Listed in VI.3; Refer to <i>STORE-Appendix R</i> ; Removed from Vol I
VI.3.7	Radiation Treatment Discontinued Early	Listed in VI.3; Refer to <i>STORE-Appendix R</i> ; Removed from Vol I
VI.3.8	Location of Radiation Treatment	Listed in VI.3; Refer to <i>STORE-Appendix R</i> ; Removed from Vol I
VI.3.9	Reason for No Radiation	Listed in VI.3; Refer to <i>STORE-Appendix R</i> ; Removed from Vol I
NEW	Systemic Therapy - First Course of Treatment	Added section numbered VI.4; Added definition; Refer to SPM; Standard Setter Difference; and CCR Specific Coding Instructions; Combined VI.4, VI.5, VI.6, and VI.7 into this section
VI.4	Chemotherapy - First Course of Treatment	Combined into new VI.4 Systemic Therapy - First Course of Treatment
VI.4.1	Names of Chemotherapeutic Agents	Removed from Vol I; Covered in SPM
VI.4.2	Date of Chemotherapy	Removed from Vol I; Covered in SPM
VI.4.3	Chemotherapy Codes	Removed from Vol I; Covered in SPM
VI.5	Hormone (Endocrine) Therapy - First Course of Treatment	Combined into new VI.4 Systemic Therapy - First Course of Treatment
VI.5.1	Hormones	Removed from Vol I; Covered in SPM
VI.5.2	Date of Hormone Therapy	Removed from Vol I; Covered in SPM
VI.5.3	Hormone Therapy Codes	Removed from Vol I; Covered in SPM

VI.6	Immunotherapy (Biological Response Modifier Therapy) - First Course of Treatment	Combined into new VI.4 Systemic Therapy - First Course of Treatment	
VI.6.1	Immunotherapy Agents	Removed from Vol I; Covered in SPM	
VI.6.2	Date of Immunotherapy	Removed from Vol I; Covered in SPM	
VI.6.3	Immunotherapy Codes	Removed from Vol I; Covered in SPM	
VI.7	Transplant/Endocrine - First Course of Treatment	Combined into new VI.4 Systemic Therapy - First Course of Treatment; Added CCR Specific Coding Instructions	
VI.7.1	Date of Transplant/Endocrine Procedure	Removed from Vol I; Covered in SPM	
VI.7.2	Transplant/Endocrine Procedures Codes	Removed from Vol I; Covered in SPM	
VI.8	Other Therapy - First Course of Treatment	Renumbered to VI.5; Refer to SPM	
VI.8.1	Date of Other Therapy	Removed from Vol I; Covered in SPM	
VI.8.2	Other Therapy Codes	Removed from Vol I; Covered in SPM	
NEW	Date of Initial RX Summary	Added section numbered VI.6; Refer to SPM; Added CCR Specific Guidelines	
VI.9	RX Summary - Treatment Status	Renumbered to VI.7; Refer to SPM	
VI.10	Protocol Participation	Renumbered to VI.8; Added link to Text - Remarks	
Part VII.	Follow-Up	N/A	
VII.1	Follow-Up Information	Removed sub-bullets under second guideline	
VII.1.3	Current Status of Follow-Up Information	Removed from Vol I; Covered in VII.1	
VII.1.4	Shared Follow-Up	Removed from Vol I; Covered in VII.1	
VII.2.1	Date of Last Follow-up or Death	Refer to SPM	
VII.2.2	Vital Status	Refer to SPM	
VII.2.3	Date of Last Cancer (Tumor) Status	Refer to SPM	
VII.2.4	Cancer (Tumor) Status	Refer to SPM	
VII.2.5	Quality of Survival	Removed from Vol I; Not supported since 2003	
VII.2.6	Last Type of Follow-Up	Renumbered to VII.2.5	
VII.2.6.1	Last Type of Tumor Follow-Up	Renumbered to VII.2.5.1	
VII.2.6.2	Last Type of Patient Follow-Up	Renumbered to VII.2.5.2	
VII.2.7	Last Follow-Up Facility	Renumbered to VII.2.6	
VII.2.8	Next Type Follow-Up	Renumbered to VII.2.7	
VII.2.9	Follow-Up Physician	Renumbered to VII.2.8; Added link to <i>Entering Physician NPI Codes</i>	
VII.2.10	Date of First Recurrence	Renumbered to VII.2.9; Refer to SPM	

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Appendix C	Codes for Countries C.1 - Alphabetical and C.2 - Code Order	Refer to <i>SPM-Appendix B-Country and State Codes</i> ; Removed Appendix
Appendix D	Residency of Military Personnel	Renumbered to Appendix C - Residency of Military Personnel
Appendix E	Codes for Religions E.1 - Alphabetical and E.2 - Code Order	Renamed to Codes for Religions; Removed Code Order table
Appendix F	Patient Information Sheet	Renumbered/Renamed to Appendix A - Patient Notification of Reportable Neoplasm
Appendix G	Codes for Casefinding	Refer to ICD-10-CM Casefinding List; Removed Appendix
Appendix H	Codes for California Counties H.1 - Alphabetical and H.2 - Code Order	Renumbered/Renamed to <i>Appendix B</i> - <i>Codes for California Counties</i> ; Removed Code Order table
Appendix I	Common Acceptable Symbols and Abbreviations I.1 - Term Order and I.2 - Abbreviation Order	Refer to NAACCR Abbreviations and Acronyms_within Vol I; Removed Appendix
Appendix J	Spanish Surnames	Renumbered to Appendix D - Spanish Surnames
Appendix K.1	STORE Surgery Codes for 2010- 2022	Refer to SPM; Removed Appendix
Appendix K.2	STORE Surgery Codes for 2023+	Refer to SPM & SPM-Appendix C - Site-Specific Coding Modules within Vol I; Removed Appendix
Appendix L	Data Alerts and Data Memos	Renumbered to Appendix G - Data Alerts and Data Memos
Appendix M	Q-TIPS	Renumbered to <i>Appendix H - Q-Tips;</i> Added 2024/2025 Q-Tips
Appendix N	Data Items and their Required Status	Reference CCR Volume II, Standards for Automated Reporting in Vol I; Removed Appendix
Appendix O	Race and Nationality O.1 - Alphabetical and O.2 - Code Order	Refer to SPM-Appendix D - Race and Nationality Descriptions; Removed Appendix
Appendix P	National Provider Identifier (NPI) Codes	Combined into Vol I, III.3.13.2; Removed Appendix
Appendix Q	Appendix Q - Site-Specific Data Items (SSDIs)	Renumbered to <i>Appendix F</i> - <i>Site-Specific Data Items</i> (<i>SSDIs</i>); Lists SSDIs required by CCR for CoC facilities only (All other SSDIs are required by ALL facilities)
Appendix R	Coding Resources	Renumbered to <i>Appendix I - Coding Resources</i> ; Added note for historical manuals; Updated Resources
Appendix S	Historical Coding and Staging Manual Requirements for CCR	Removed Appendix; Covered in Appendix I
Appendix T	Text Documentation Guidelines	Combined into Vol I Part IV - Text Documentation; Removed Appendix

Part I. Introduction

Part I of Volume I introduces the user to the role of the cancer registry, the California Cancer Registry, as well as state cancer reporting requirements. Included in the state requirements: confidentiality, casefinding, reporting by both hospital and non-hospital facilities, and cases diagnosed and treated elsewhere.

I.1 Reporting Cancer Statistics

The systematic gathering of information about the incidence of cancer in designated populations is an indispensable tool in the struggle to contain the disease. With access to reliable statistics on the occurrence of several types of cancer, the people affected, the treatment provided, and other epidemiological factors, researchers and public health officials are better able to identify problems and evaluate remedies. Findings from such studies include possible environmental influences on the development of neoplasms, the susceptibility of certain ethnic and social groups to particular neoplasms, the need for oncology services in various locales, and the appropriateness of diagnostic and therapeutic procedures.

I.1.1 Role of the Cancer Registry

Many California hospitals have had their own cancer registries since the 1950's in accordance with guidelines established by the American College of Surgeons (ACS) and its requirements for accreditation of oncology services. The main purpose of a hospital registry is to provide physicians with the data needed to maintain quality of care through peer review and to compare performance with recognized standards. However, a more comprehensive level of reporting is required by state law and that level is supported by the California Cancer Registry and its statewide database system, SEER*DMS.

I.1.2 The California Cancer Registry

Information from hospital registries and other reporting sources is gathered by the California Cancer Registry (CCR) primarily for use in epidemiological research and for monitoring the occurrence of cancer in the state. A unit in the Chronic Disease Surveillance and Research Branch of the California Department of Public Health, the CCR was established in 1947 as a pilot study to determine the feasibility of basing a central registry on data reported by hospitals. The study was successful, and the registry gradually expanded its coverage from nine hospitals to thirty-six, most of which were in the San Francisco Bay area and Los Angeles County. As a result, valuable statistics were developed about the survival of cancer patients. However, since the data did not apply to a defined segment of the population, it was not possible to calculate the incidence of cancer. A section covering the population of Alameda County was therefore added to the registry in 1960. When the National Cancer Institute (NCI) undertook its Third National Cancer Survey in 1969, the population-based registration was extended to the entire San Francisco-Oakland Standard Metropolitan Statistical Area (SF-O SMSA) consisting of Alameda, Contra Costa, Marin, San Francisco, and San Mateo counties. Support for the SF-O SMSA registration was subsequently provided by the NCI's Surveillance, Epidemiology and End Results (SEER) Program. Established in 1973, SEER is among the largest population-based registries in the Western world, covering approximately 159 million people in twenty-two designated regions of the United States. Twenty of which contribute cases to the current SEER research data.

Expansion of the registration to the SF-O SMSA produced several important benefits. It strengthened the DHS's ability to estimate the incidence of cancer in California, ascertain risk factors in the

occurrence of the disease, study variations in risks among different ethnic groups and social classes, identify changes in the incidence of various forms of cancer in subgroups of the population, and study long-term changes in the interrelationship of incidence, early diagnosis, treatment, length of survival, and mortality for a greater understanding of cancer. In addition, it greatly increased the number of cases available to researchers for epidemiological studies of human cancer and its relationship to the environment, genetics, cancer in varied species, and other data items. Because of these benefits, the CCR's coverage was extended to the State's entire population, which in 2025 is projected to be over 42.5 million people.

I.1.3 State Cancer Reporting Requirements

The State of California has specific cancer reporting requirements. An overview of California's Health and Safety Code and related information is outlined below.

Provisions of the <u>California Health and Safety Code</u> enacted in 1985 (Sections 103875 and 103885) mandate the establishment of a statewide system of cancer reporting. The purpose of the system is to conduct a Program of epidemiological assessments of the incidence of cancer, with a view to identifying cancer hazards to the public health and their remedies. Under the code, any hospital or other health care facility that diagnoses or treats cancer patients within an area designated as a cancer reporting area shall report each case of cancer to the department or the authorized representative of the department.

The Official California Code of Regulations implement the state statutes and have the same force of law as court decisions or legislation, is located on the <u>Reporting Legislation and Legislation</u> section on the <u>California Cancer Registry website</u>.

Guideline:

• It is the reporting facility's responsibility to inform patients that their cancer diagnosis has been reported to the California Cancer Registry as required by regulations that govern the cancer reporting law. Patient Notification of Reportable Neoplasm document has been developed by the California Department of Public Health, which may be used to inform patients. Refer to <u>Appendix A - Patient Notification of Reportable Neoplasm</u>.

Note: A reporting facility may modify this information sheet if they so choose.

I.1.4 Confidentiality

The <u>California Health and Safety Code</u> stipulates that the identity of patients whose cases are reported to the CCR must be held in the strictest confidence. Information that could be used to identify a patient may not be released to or discussed with anyone other than authorized personnel at the reporting facility or other reporting sources, unless prior informed consent is received from the patient. Section 100330 of the code states:

All records of interviews, written reports and statements procured by the state Department of Public Health or by any other person, agency or organization acting jointly with the state department, in connection with special morbidity and mortality studies shall be confidential insofar as the identity of the individual patient is concerned and shall be used solely for the purposes of the study. The furnishing of such information to the state or its authorized representative, or to any other cooperating individual, agency or organization in any such special study, shall not subject any person, hospital, sanitarium, rest home, nursing home, or other organization furnishing such information to any action for damages.

- The CCR also has a policy of maintaining the confidentiality of any information that could be used to identify the caseload of a specific facility or physician.
- Under certain circumstances, confidential information may be released for research purposes without the patient's consent.
 - Legal provisions for these exceptions to the rules of confidentiality are contained in the <u>Information Practices Act, Civil Code 1798.24</u>. Refer to <u>Appendix A - Patient</u> <u>Notification of Reportable Neoplasm</u> for a sample document, for use in notifying patients that cancer is reportable.
- For more information regarding the CCR's confidentiality policy, refer to the CCR web site: <u>http://www.ccrcal.org</u>.

I.1.5 Casefinding

Casefinding (case ascertainment): The process of identifying eligible cases through review of sources documents and case listings. Comprehensive casefinding includes investigating all diagnostic and therapeutic services to look for active cancer cases. Casefinding covers a range of cases that need to be accessed to determine whether they are reportable or not.

Although exact procedures might vary from reporting facility to reporting facility, they ordinarily involve careful monitoring of the records kept by the departments that usually provide diagnostic and treatment services to patients with cancer.

Guidelines:

- Current and previous casefinding lists are available on the SEER website: <u>https://seer.cancer.gov/tools/casefinding/</u>.
 - Use the casefinding lists to screen prospective reportable cancer cases.
 - A casefinding list is **not** the same as a reportable list.
 - The casefinding lists are used to identify cases seen at the reporting facility with benign or malignant tumors and/or conditions, which are reportable to the CCR. This aids in the prevention of missed cases.

I.1.5.1 Casefinding Procedures

Registrars must rely on several sources of documentation to identify all cancer cases diagnosed and/or treated at the facility. More than one type of documentation is generally needed to capture all of the required information for each patient.

Guidelines:

- Investigate every department or area where a patient might be seen or treated to identify eligible cases.
 - Sources differ depending on the facility type, services provided, and size.
 - Facility registries should limit the number of casefinding personnel to those who are familiar with the reportable diagnoses. This helps to ensure complete casefinding.

Note: Other Standard Setters such as the American College of Surgeons (ACS) and/or the facility's cancer committee may require registrars to report certain cases in addition to what the CCR requires.

- Effective communication skills are essential in the casefinding process. Registrars will likely interact with other facility staff while looking for and obtaining information on eligible cases.
 - Explain the purpose to departments and requests for information.
 - Describe the nature of cancer case reporting and the function of the state registry. Underscoring:
 - How accurate, timely, and complete data collected at the provider level benefits the public, the facility, and the patient with cancer.
 - How cooperation of ancillary departments involved in cancer care is critical to achieve maximum casefinding results.
 - Open communication extends to the relationships that registrars have among themselves, with fellow members of the cancer committee, and with their regional registry representatives.
 - Regional registry representatives serve as liaisons between the CCR and the reporting facility.
 - Registrars are encouraged to contact their regional registry representative when questions and concerns arise.

I.1.5.2 Casefinding Sources

The hospital and non-hospital departments listed below identify the areas within a facility where eligible cases might be found. Not all facilities contain the departments listed.

Guidelines:

- Include all casefinding sources when searching for reportable cases.
- Each of the following departments are potential sources for finding eligible cancer cases:
 - Laboratory
 - o Health Information Management/Medical Records
 - Other departments used in Casefinding:
 - Outpatient, Clinic and Ambulatory Care Services/Surgery
 - Oncology-Related Services
 - Staff Physician's Offices
 - Long-Term Care Facility/Skilled Nursing Facility
 - Hospice
 - Emergency Department (ED)

I.1.5.2.1 Casefinding - Laboratory

The laboratory department is generally the primary casefinding source for eligible cases to be included in the registry database. Personnel who are knowledgeable in cancer case reporting must review pathology reports, including histology, cytology, hematology, bone marrow, and autopsy findings.

Guidelines:

• Ways to accomplish the review of all laboratory reports:

- Manually review every report to identify eligible cases.
- If the pathology reports are computerized, the registrar can request a list.
- Pathology reports, including histology, cytology, hematology, bone marrow, and autopsy findings.
 - Since pathologic studies are made for most patients suspected of having cancer, most reportable cases can be found by reviewing or obtaining copies of reports with positive or indicative diagnoses.
- The pathology department may have distinct divisions with subspecialties such as dermatopathology, eye pathology, oral pathology, GYN pathology and/or pediatric bone marrow pathology.
 - Each division should be reviewed for reportable cases of cancer.
- Experience demonstrates that trained registry personnel perform the most complete and accurate screening of pathology reports.
 - A registrar should audit the findings to ensure casefinding is complete in the event someone outside the registry reviews the pathology reports.

I.1.5.2.2 Casefinding - Health Information Management (HIM)/ Medical Records

The secondary source of cancer casefinding is the HIM/Medical Records Department, especially through the Disease Index. The Disease Index is usually a list run periodically that is either hard copy or in an electronic format. It is typically in medical record or ICD-O code order. The value of the Disease Index cannot be overemphasized.

Guidelines:

- Disease Indexes (See casefinding lists, located on the SEER website: <u>https://seer.cancer.gov/tools/casefinding/</u>, for applicable ICD-10-CM codes used in health information/medical record departments).
- The index should include the patient name, medical record number, and ICD diagnosis codes.
 - Supplementary information may include admission and/or discharge dates, length of stay, ICD codes for the associated disease and procedures, and the physician's name and/or license/ID number.
 - When requesting the Disease Index, the cancer registrar should specify the reportable ICD cancer codes to identify pertinent inpatient and outpatient visits.
 - Not every reportable case has a positive histological diagnosis at every facility.
 - Regularly, a case is histologically diagnosed at one hospital or in a physician's office and the patient is admitted to another facility for treatment.
- Surgery reports.
- Health Information Management/Medical Records Departments can also be a source of information associated with discharges, specifically discharges following a death (death log). Regular review of all hospital deaths reduces the likelihood of Death Certificate Only (DCO) cases in the future.

I.1.5.2.3 Casefinding - Other Sources

Other sources of eligible case ascertainment include inpatient/outpatient departments such as staff physician offices, clinics (ambulatory care/surgery), oncology-related services (diagnostic imaging), emergency departments, long-term care, and hospice facilities. Casefinding procedures should be established for eligible cases.

Guidelines:

- Other facilities and/or departments with potential sources for finding eligible cancer cases:
 - o Outpatient, Clinic and Ambulatory Care Services/Surgery
 - Disease Index
 - Daily facility and clinic discharges
 - Surgery and visit logs
 - Billing form copies (contain both diagnosis and ICD codes)
 - o Oncology-Related Services
 - Radiation therapy logs
 - Nuclear medicine logs
 - Radiology logs, including logs of scans
 - Radiation and chemotherapy appointment books/logs
 - Staff Physician's Offices
 - Disease Index
 - o Long-Term Care Facility/Skilled Nursing Facility
 - Admissions and discharges
 - Hospice
 - Monitor admissions to facility hospice units for casefinding purposes. Collect eligible cases where:
 - Palliative or comfort care is provided.
 - Active cancer cases whether patients have been diagnosed and/or have received treatment at the facility or not.
 - Emergency Department (ED)
 - ED logs
 - Death Certificates

I.1.5.3 Casefinding - Audits

Periodic casefinding audits are strongly encouraged for every reporting facility to confirm that every eligible case is identified and reported.

- Develop a system of internal review.
 - \circ Speak with other facility registrars or their field representatives for ideas.
- When significant changes occur in the annual reporting total average, look for changes in services and/or staffing.
- Address fluctuations in reporting totals with regional representatives as soon as they are noted.

I.1.5.4 Casefinding for Follow-Up

To meet the requirements of the State's cancer reporting system, it is necessary to periodically determine the vital status and condition of registered patients. One method of obtaining this information is through the casefinding process.

Guidelines:

- Reporting facilities must have a systematic method of identifying patients who are re-admitted to the facility or who are treated on an outpatient basis, whether for the reported cancer or for another condition.
 - This information can be used to update patient's vital status and condition.
 - Regular review of all hospital deaths reduces the likelihood of Death Certificate Only (DCO) cases in the future.

Refer to *Follow-Up Information* for additional follow-up information.

I.1.6 Reporting in California

The reporting facility must report every reportable case first seen as an inpatient or outpatient, either with evidence of cancer or for cancer-directed treatment, on or after the date that mandatory reporting was declared for the region (the region's reference date). Refer to the <u>Regional Registry Reference</u> <u>Date Guide</u> for the specific date when mandatory reporting began in each region.

Cancer is defined by the <u>California Health and Safety Code</u> for registry purposes, as "all malignant neoplasms, regardless of the tissue of origin, including malignant lymphoma, Hodgkin disease, and leukemia, but excluding basal cell and squamous cell carcinoma of the skin."

Information about cancer cases is reported to the CCR in the form of abstracts, which summarize pertinent information about individual cases. See the <u>California Cancer Reporting Systems</u> <u>Standards, Volume II, Standards for Automated Reporting</u> for data item requirements. If in doubt about how certain data items should be completed, the regional registry should be contacted.

- Every reporting facility must report all cases, inpatient or outpatient, admitted on or after the regional registry's reference date with a neoplasm classified in the morphology section of *ICD-O-3.2 (International Classification of Diseases for Oncology, Third Edition, (2000),* <u>Second Revision</u> as malignant or in-situ, including those discovered at an autopsy.
 - The only exceptions are certain carcinomas of the skin. See the <u>CCR Reportability</u> <u>Guide - Reportable</u>.
- Identifying the primary neoplasm and single or multiple tumors:
 - For cases or tumors diagnosed January 1, 2018 and forward, refer to the current <u>Solid</u> <u>Tumor Rules</u>.
 - Do not use the Solid Tumor Rules to determine reportability, stage, or to assign grade.
 - For hematopoietic and lymphoid cases diagnosed January 1, 2018 and forward, please refer to the <u>Hematopoietic and Lymphoid Neoplasm Database and Hematopoietic &</u> <u>Lymphoid Neoplasm Coding Manual</u>.
- Identifying reportable diagnoses based on ambiguous diagnostic reportable terms.

- The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for determining *ambiguous diagnostic reportable terms*.
- Determining reportability of pathology and consultation only cases:
 - Consult Only abstract *required*: If the consulting facility is responsible for treatment decisions or follow-up, an abstract is required.
 - Consult Only abstract *not required*: If the consulting facility is confirming a diagnosis made elsewhere, rendering a second opinion, or recommending treatment to be delivered, the regional registry must be notified.

Note: When in doubt about whether to report the case, contact your regional registry for guidance.

Reportable Cases:

- A reportable cancer or tumor must be reported to the CCR if it is diagnosed by any physician/health care practitioner, including:
 - Pathologist
 - o Radiologist
 - Surgeon
 - Dentist
 - Podiatrist
 - Any other healthcare practitioner diagnosing or providing treatment for cancer patients.

Examples: Physician Assistant (PA), and Nurse Practitioner (NP), Nurse Midwife, Resident, and Fellows.

- Every required data item must be completed, and the entries must be accurate, concise, and clear.
- All information about diagnostic workup, staging and treatment should be reported. This includes diagnosis/staging/treatment done elsewhere but documented in the reporting facility medical record.
 - Whatever reporting software is used, rules for entering data must be followed precisely.
- Coded data items **must** be supported by text documentation on the abstract. Text documentation is an essential component of a complete electronic abstract. Text summaries should be as concise as possible. See <u>*Text Documentation*</u> for more information.
- Benign/Borderline Brain and CNS Tumors

Standard Setter Difference:

- Reportability dates for Benign/Borderline Brain and CNS Tumors.
 - California Cancer Registry began collecting the following cases January 1, 2001 and forward.
 - Benign Schwannoma:
 - Reportable for cases diagnosed January 1, 2004 and forward for sites C722-C725.

- Expanded for cases diagnosed January 1, 2011 and forward to include site C720.
- National implementation began with cases diagnosed on January 1, 2004 and forward.
 - In 2002, <u>Public Law 107-260</u> required the National Program of Cancer Registries (NPCR) to expand their primary brain tumor data collection to include tumors of benign and uncertain behavior. This began with cases diagnosed January 1, 2004 and forward.

Non-Reportable Cases:

- Hospice Only
- Patients receiving long-term therapy with a history of cancer, but no current evidence of cancer.
- Cancer Conference (Tumor Board) presentation only
- Consult Only and facility is <u>reviewing information only</u> to confirm a diagnosis made elsewhere, rendering a second opinion, or recommending treatment which will be done elsewhere. See <u>Determining reportability of pathology and consultation only</u> cases above for more information.
- Catheter placement for cancer therapy only
- Patients receiving transient care
- Outpatient blood draw

REQUIRED METHOD OF REPORTING BY CLASS OF CASE IS OUTLINED IN THE TABLES BELOW

Analytic Cases

Initial Diagnosis at Reporting Facility

Class of Case	Required by CCR	Reporting Method
00	Yes	Abstract
10	Yes	Abstract
11	Yes	Abstract
12	Yes	Abstract
13	Yes	Abstract
14	Yes	Abstract
20	Yes	Abstract
21	Yes	Abstract
22	Yes	Abstract

Non-Analytic Cases

Patient appears in person at Reporting Facility; Both initial diagnosis and treatment elsewhere.

Class of Case	Required by CCR	Reporting Method
30	*Yes (see <u>Class of</u> <u>Case</u> for exceptions)	Abstract
31	No	NR
32	Yes	Abstract
33	No	NR
34	Yes	Abstract
35	Yes	Abstract
36	Yes	Abstract
37	Yes	Abstract
38	Yes	Abstract

Non-Analytic Cases

Patient does not appear in person at Reporting Facility

Class of Case	Required by CCR	Reporting Method
40	No	NR
41	No	NR
42	Yes	Abstract

Non-Analytic Cases

Regional Registry Responsibility Only

Class of Case	Required by CCR	Reporting Method
43	Yes	Abstract
49	Yes	Abstract

Key to Reporting Method:

Abstract - Full abstract required **NR** - Not Reportable

I.1.6.1 Entering Dates

Dates transmitted between facility registries and central registries changed to improve the interoperability or communication of cancer registry data with other electronic record systems. Registry software may display dates in the traditional manner or in the interoperable format. Consult your software vendor for specific data entry instructions.

- **Traditional dates** are displayed in MMDDCCYY form, with 99 representing unknown day or month portions, and 99999999 representing a completely unknown date. In traditional form, some dates also permit 888888888 or 00000000 for special meaning.
- **Interoperable dates** are displayed in CCYYMMDD form, with the unknown portions of the date filled with blank spaces. An allowable date must contain the year.

Description	Traditional Date	Interoperable Date

FULL DATE KNOWN	MMDDCCYY	CCYYMMDD
MONTH AND YEAR KNOWN	ММ99ССҮҮ	ССҮҮММbb
YEAR ONLY KNOWN	9999CCYY	CCYYbbbb
UNKNOWN DATE	99999999	bbbbbbbb
h- blonk		

b= blank

Guidelines:

- Vague Dates: Enter an approximate date when the exact date cannot be determined. At a minimum, a year of diagnosis is required for all analytic cases (*Class of Case* 00-22). The year of diagnosis must be known or estimated and cannot be blank or unknown. The date of first cancer directed therapy may be used as the date of diagnosis if the therapy was initiated before definitive confirmation of the diagnosis. Documentation must be provided for the basis of the estimated date.
- Approximate Dates: At a minimum, a year of diagnosis is required for all analytic cases (*Class of Case* 00-22). Use the date treatment was started if the patient receives a first course of treatment before a definitive diagnosis. Documentation must be provided for the basis of the estimated date. Use the following coding procedures for estimating dates relating to diagnosis.
- **Estimating Year:** *Use whatever information is available to calculate the year.* Enter the year of admission when there is no basis for estimation.

Terms	Code To
COUPLE OF YEARS AGO	Two years ago
FEW YEARS AGO	Three years ago

• Estimating Month: *Use whatever information is available to calculate the month*. Leave the month blank if there is no basis for approximation.

Terms	Code To
RECENTLY	Enter the month and year of admission, and unknown ("99" or leave blank depending on your registry software) for the day. If patient was admitted during the first week of a month, enter the previous month
SEVERAL MONTHS AGO	Assume the case was first diagnosed <u>three months</u> before admission with the day unknown when the patient was not previously treated or if a course of treatment started elsewhere was continued at the reporting facility
SPRING	Enter as April
SUMMER	Enter as July
FALL OR AUTUMN	Enter as October
WINTER	Enter as December or January based on available information i.e. end/beginning of year
EARLY IN THE YEAR	Enter as January

MIDDLE OF THE YEAR	Enter as July
END OF THE YEAR	Enter as December
LATE IN THE YEAR	Enter as December

b= blank

I.1.6.2 Reporting by Non-Hospital Treatment Centers

Not all abstracting requirements apply to freestanding radiation therapy centers and other cancer treatment centers that are not part of hospitals and do not have inpatient facilities. Usually, patients seen at these facilities have been hospitalized elsewhere previously, and the treatment center is not the primary source for detailed information about their diagnostic workups. However, case reports from such facilities afford a quality check on the hospitals' reports and, even more important, provide data that complete the information about the patient's first course of treatment. Without these reports, statewide data on patterns of care would not be accurate or clinically useful.

Guidelines:

- When submitting abstracts, treatment centers must provide complete patient identification and treatment information performed at their facility, but they are not required to fill in text data items for diagnostic procedures or other treatment that was performed elsewhere.
- Recording stage is also important. When planning treatment, the radiation therapist often performs the most thorough assessment of stage available for the case.
- The treatment center's abstract must be prepared in the same electronic format used by other facilities.

I.1.6.3 Cases Diagnosed and Treated Elsewhere

Reporting requirements for cases diagnosed and treated elsewhere are less stringent than those for other cases. The reporting facility's medical record often does not contain the required data, or contains only secondhand data.

- The CCR requires that most non-analytic cases be abstracted and submitted.
 - For definitions of non-analytic, analytic cases, and Class of Case, see <u>Class of Case</u>.
 - For instruction on how the case should be submitted, see <u>*Reporting in California*</u>.
- Report all information included in your facility's medical record. If the electronic medical record system used by your facility has the ability to view the medical records from outside facilities, it is not necessary to look for missing information in those outside records, although a facility may choose to do so.
- All information reported must be documented in the appropriate text fields. See <u>*Text</u></u> <u><i>Documentation*</u>.</u>
- The place of diagnosis, the date first seen at the reporting facility, and the reason the patient presented at the reporting facility should also be documented in text.

- Even though information for many required data items might not be available, all the data items must be completed.
- If necessary, enter the codes for UNKNOWN or NONE.

Part II. Reportable Neoplasms

Part II of Volume I contain the CCR Reportability Guide, information on how to identify primary tumors, ambiguous terminology, what to do with path or Consult Only cases, hematopoietic neoplasms, and benign/borderline and CNS tumor reporting. Additionally, abstracting accession and sequence number instructions are also included.

Guidelines:

- For additional information on topics listed in this section, please refer to <u>Appendix H Q-Tips</u>, for a list of topics.
- CCR Q-Tips are available in the CCR learning management system FLccSC. To access your existing FlccSC account or Register as a new FLccSC User click here: <u>FLccSC Fundamental</u> <u>Learning Collaborative for the Cancer Surveillance Community</u>.
- See <u>Appendix I Coding Resources</u> for a list of helpful coding resources for registrars to reference when abstracting. These are intended to be used as a supplement to this Volume.

II.1 CCR Reportability Guide - Reportable

Refer to the reportability guide below for information on specific histologies and sites for tumors that are reportable to the CCR.

Sources: The <u>SEER Program Coding and Staging Manual</u> and <u>SPM-Appendix E - Reportable and</u> <u>Non-reportable Examples</u> are to be used for determining reportable diagnoses for **Solid Tumors**, including reportable diagnoses based on ambiguous diagnostic reportable terms, with the following CCR exceptions:

- CCR reportability date for benign brain tumors is 2001. This included benign schwannoma's, 9560/0. In 2004, benign brain tumors (including schwannoma's) became required for collection by SEER and CDC registries as well.
- The CCR reportability date for AIN II, VAIN II, and VIN II is 01/01/2022 and forward. This differs from SEER's requirement of 01/01/2021 and forward.
- The term "pre-invasive" is accepted by the CCR as a reportable term that indicates in-situ behavior (/2).
- The CCR provides additional reportability clarifications for Skin (C440-C449):
 - Basal and squamous cell carcinoma of the skin of the **genital organs** (vagina, clitoris, labium, vulva, prepuce, penis, and scrotum) are reportable.
 - Adnexal carcinomas (e.g., carcinomas of the sweat gland, sebaceous gland, ceruminous gland, and hair follicle), adenocarcinomas, lymphomas, melanomas, sarcomas, and Merkel cell tumors are reportable regardless of site are reportable.
 - Any carcinoma arising in a hemorrhoid is reportable since hemorrhoids arise in mucosa, not in skin.

Standard Setter Differences:

- SEER and CoC/STORE differences in reportability:
 - CoC/STORE may have different rules on Reportability, and assignment of Date of Diagnosis for Liver cases based on LI-RADS 4 or LI-RADS 5. However, the CCR and SEER rules take precedence in Reporting and assignment of Date of Diagnosis.
 - CoC/STORE may have different rules on Reportability, and assignment of Date of Diagnosis for Prostate cases based on PI-RADS 4 or PI-RADS 5. However, the CCR and SEER rules take precedence in Reporting and assignment of Date of Diagnosis.

Source: For Hematopoietic and lymphoid neoplasms, see the Reportability Instructions in the following link: <u>http://seer.cancer.gov/seertools/hemelymph</u>.

II.2 CCR Reportability Guide - Non-Reportable or Historically Reportable

Refer to the reportability guide below for information on specific histologies and sites for tumors that are either not reportable or historically reportable to the CCR.

Non-Reportable or Historically Reportable Diagnoses:

- Appendix (C181)
 - Carcinoid tumors, NOS of the appendix, histology 8240 with borderline behavior/1, became OBSOLETE beginning 01/01/2015+
- Borderline Ovarian (C569)
 - Histologies 8442/1, 8451/1, 8462/1, 8472/1, and 8473/1, not reportable 01/01/2016+
 - Reportable with behavior /1 between 01/01/2001 through 12/31/2015.
 - Reportable with behavior /3 before 01/01/2001.
- **Cervix** (C530-C539)
 - Behavior /2 were reportable before 01/01/1996:
 - Carcinoma in-situ of the cervix (CIS) (including squamous cell & adenocarcinoma).
 - Cervical intraepithelial neoplasia grade III (CIN III).
 - Cervical intraepithelial neoplasia with severe dysplasia (CIN III).
- Gastrointestinal stromal tumors (GIST)
 - Prior to dx 01/01/2021, GIST was reportable when:
 - Documented as being in-situ.
 - Documented as NOS with multiple foci, lymph node involvement, or metastasis.
 - Patient undergoing treatment as if it is malignant.
- Liver (C220)
 - Do not report cases based only on an LI-RADS category LR-3.
- Lymphoma in-situ, behavior /2 has always been non-reportable.

- See <u>*Historic Newly Reportable Hematopoietic Diseases (NRHD)*</u> for cases 01/01/2001 to 01/01/2010.
- **Prostate** (C619)
 - Prostatic intraepithelial neoplasia high grade, grade III (PIN III), 8148/2 has always been non-reportable.
- **Renal Pelvis, ureters, urinary bladder part of urethra** Papillary urothelial neoplasm of low malignant potential (PUNLMP) are not reportable.
- Skin (C440-C449) histologies 8000-8110, has always been non-reportable.
 - Basal cell carcinomas of the skin.
 - Epithelial carcinomas of the skin.
 - Papillary carcinomas of the skin.
 - Squamous cell carcinomas of the skin.
 - Squamous intraepithelial neoplasia III (SIN III) (8077) of skin sites coded to C44_.
 - Early or evolving melanoma of any type was <u>not</u> reportable if diagnosed between 01/01/2018 12/31/2020.
- **Thyroid** (C739)
 - Non-invasive follicular thyroid neoplasm with papillary like nuclear features is a synonym for encapsulated follicular variant of papillary thyroid carcinoma, 8343/2, was reportable if diagnosed between 01/01/2017-12/31/2020.
- **Thymus** (C379)
 - Prior to dx 01/01/2021 thymoma's were reportable when:
 - Documented as NOS with multiple foci, lymph node involvement, or metastasis.
- Venous angioma/Venous hemangioma Venous angiomas are not reportable wherever they arise. The primary site for venous hemangioma arising in the brain is blood vessel (C490). The combination of 9122/0 (Venous hemangioma) and C490 is not reportable.

Note: This is a venous abnormality, previously referred to as venous angiomas and currently referred to as developmental venous anomalies (DVA).

Part III. Identification

Part III of Volume I is comprised of the sub-sections identifying the registry, the patient, and the case. Included in each subsection are detailed instructions on coding facility specific items, patient demographics, and case specific items such as date of diagnosis or class of case, to name a couple.

- For additional information on topics listed in this section, please refer to <u>Appendix H Q-Tips</u>, for a list of topics.
- CCR Q-Tips are available in the CCR learning management system FLccSC. To access your existing FlccSC account or Register as a new FLccSC User click here: <u>FLccSC Fundamental</u> <u>Learning Collaborative for the Cancer Surveillance Community</u>.
- See <u>Appendix I Coding Resources</u> for a list of helpful coding resources for registrars to reference when abstracting. These are intended to be used as a supplement to this Volume.

III.1 Registry Information

This includes reporting facility specific data items such as the reporting facility identification number, abstractor, and ACS approval flag data items. The information is used by the reporting facility and regional registries for facility specific identification purposes.

III.1.1 Abstractor

Enter the abstractor's initials, beginning in the left most space. If there are fewer than three initials, leave the trailing spaces blank.

Coding Instructions:

- Each reporting facility must submit a list of names and initials of all abstractors in their facility, including temporary staff, beginning in January 2007.
- Changes to this list must be submitted to the region when specified abstractors no longer create abstracts at the facility, or when new abstractors are added.

III.1.2 Reporting Facility

Enter the reporting facility's CCR assigned reporting facility code or the facility's name.

Coding Instructions:

- Refer to the most current <u>California Reporting Facility Codes</u> lists, located on the CCR website <u>https://www.ccrcal.org</u>, Registrar Resources, Reporting Cancer in California, Volumes I-V.
 - Lists are presented in both alphabetical and code order.

III.1.3 CoC Accredited Flag

The CoC Accredited Flag is assigned at the point and time of data abstraction to label an abstract being prepared for an analytic cancer case at a facility accredited by the Commission on Cancer (CoC). This data item is required by the CCR for cases diagnosed January 1, 2018 and forward.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *CoC Accredited Flag* data item.

III.2 Patient Information

This section contains instructions on how to collect patient specific demographic information.

III.2.1 Name

Follow the guidelines below for entering the patient's name. Accurate patient information is important for matching data in the abstract with data about the patient received from other sources.

Reporting facilities must use the same rules for entering names, dates, and other information. Although reporting facility systems may have different name-related data entry requirements, the CCR requires the following information and formatting for patient name. **Source:** The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Name* data items, in conjunction with the CCR specific coding instructions below, which take priority.

CCR Specific Coding Instructions:

- First Name
 - o If the name cannot be determined or is unknown, enter "UNKNOWN" or "Unknown."

Standard Setter Difference:

- This coding instruction differs from SEER and CoC. For this data item, CCR is following the NPCR coding instruction above to pass NPCR submission edits.
- **Religious Names** Please use the following instructions when entering religious names.
 - Do not enter religious designations like Sister, Brother, or Father unless the patient's secular name is unknown.
 - If the secular name is known, enter the last name of the religious name under *Alias Last Name* data item.
 - When the religious name only is known, enter the last name under *Last Name*, the designation under *First Name*, and the religious first name under *Middle Name*.

Examples:

1. Religious name: Sister Mary Anthony and Secular name: Jane Smith

Report as:

(last name) Smith (first name) Jane (alias) Anthony

2. Religious name: Sister Mary Anthony and secular name: Smith (first name unknown)

Report as:

(last name) Smith (first name) Sister (alias) Anthony

3. Religious name: Sister Mary Anthony and secular name: unknown

Report as:

(last name) Anthony (first name) Sister (middle name) Mary

- Name Suffix A name suffix is a title that would follow the name in a letter such as Jr, Sr, III, or IV. It is frequently a generation identifier. It helps to distinguish between patients with the same name.
 - \circ Do not use punctuation.
 - Leave blank if the patient does not have a name suffix.
 - \circ $\,$ Do not use this data item to record suffixes such as MD or PhD.

- Mother's First Name Enter the pediatric patient's mother's first name in this data item.
 - Enter up to 40 characters in the Mother's First Name data item.
 - Include the hyphen or apostrophe in a name, but do not enter any other non-alphabetic characters.
 - If this name is not available, this data item may be left blank.

III.2.2 Medical Record Number

Enter the medical record number assigned to the patient at the reporting facility. For facilities using a serial numbering system, enter the latest number assigned at the time of abstracting (This will not be updated).

Coding Instructions:

- Medical record numbers can be alphanumeric.
- Do not use punctuation or leave a blank space. Enter leading zeroes that are part of the number.
- If a patient has not been assigned a medical record number at the time the abstract is prepared, certain other identifying numbers may be entered.

Examples:

- 1. Some facilities enter the log number assigned by the radiation therapy department, preceded by the letters RT, for patients who do not have a medical record number but are receiving radiation therapy.
- 2. For outpatients who are not admitted and not seen in the radiation therapy department, the assigned number can be preceded with the letters OP.
- 3. If a number is not assigned, enter a code meaningful to the facility. This data item should not be left blank.

III.2.3 Social Security Number

A patient's full social security number is critical for the identification of multiple reports of the same cancer so that they are not counted as separate cases.

Coding Instructions:

Two data items are provided:

- Nine-character data item for the number:
 - Enter the patient's 9-digit social security number (SSN).
 - Make every effort to ascertain the patient's own number. Enter it in the data items provided.
 - If the patient's own number cannot be determined, enter whatever number is available from the medical record.
 - If the social security number is not known, enter 9's.
 - The following values are not allowed:
 - First three digits cannot be 000 or 666
 - Fourth and fifth digits cannot be 00

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- Last four digits cannot be 0000
- First digit cannot be 9 (except for 999999999)

1. Social security number from face sheet: 111-22-3333

Medicare claim number: 123-45-6789B Enter 111-22-3333

2. Social security number from face sheet: 222-33-4444D5

No other numbers recorded in chart Enter 222-33-4444D5

III.2.4 Medicare Beneficiary Identifier (MBI)

Enter the Medicare Beneficiary Identifier assigned to the patient. The MBI is a randomly generated identifier that does not include a SSN or any personal identifiable information. The MBI is a step to minimize the risk of identity theft for Medicare beneficiaries and to reduce opportunities for fraud. The Medicare Beneficiary Identifier is required if available by the CCR (if the information is available to you for abstracting, it is required) for cases diagnosed January 1, 2018 and forward.

Coding Instructions:

- Enter the 11-character Medicare Beneficiary Identifier randomly assigned to the patient by Medicare.
- The Medicare Beneficiary Identifier:
 - Consists of numbers and upper-case letters.
 - Entered without dashes.

Codes (in addition to MBI):

Code	Description
BLANK	Not Available, Non-Medicare Patient, Not Applicable, or Unknown

III.2.5 Phone Number (Patient)

This data item is to be used for entering the patient's current telephone number including the area code.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Phone Number* data item.

III.2.6 Address at Diagnosis

The *Address at Diagnosis* data item is part of the patient's demographic data and has multiple uses. It indicates referral patterns and allows for the analysis of cancer cluster concerns and other epidemiological studies. The main purpose of the address data item is to identify the patient's residence at the time the cancer was first diagnosed, not the patient's current address.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Address* data items, in conjunction with the CCR specific coding instructions below, which take priority.

CCR Specific Coding Instructions:

Standard Setter Difference:

- Per SEER guidelines, a homeless or transient patient's address at the time of diagnosis would be coded to the shelter they reside at, or the hospital where diagnosis was confirmed. However, the CCR codes the county at diagnosis, and the rest of the fields as unknown. See the following instructions for CCR coding.
- If the patient is homeless or transient with no usual residence:
 - Enter the street, city and zip code as unknown but code county of residence to the county where the reporting facility is located and code the state to California.
 - Document that the patient is "Homeless" or "Transient" in the Address at Diagnosis -Supplemental data item.
 - See <u>Appendix B Codes for California Counties for California Counties</u> lists.

Note: Coding address information for homeless/transient patients in this manner is important from a research perspective. Attempting to code otherwise would be incorrect in California and would skew cluster investigations.

- See <u>Appendix C Residency of Military Personnel</u> for determining the residency of patients in the U.S. Navy or Merchant Marine when diagnosed with cancer while onboard ships or vessels.
 - Included are detailed rules for determining the region the patients are residents of for purposes of cancer reporting.

III.2.7 Marital Status

Incidence of cancer and sites of cancer have shown correlations to marital status. These patterns are also different among races. Thus, this data item is very important to researchers for the reportable neoplasm.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Marital Status* data item, in conjunction with the CCR specific coding instructions below, which take priority.

III.2.8 Sex

This data item documents the sex (gender) of the patient.

Definitions:

Intersex: A person born with ambiguous reproductive or sexual anatomy; chromosomal genotype and sexual phenotype other than XY-male and XX-female.

Transsexual: A person who has undergone (or is in the process of) surgical alteration to achieve gender opposite to their sex at birth, i.e. surgically altered gender.

Transgender/Transgendered person: A person who identifies with or expresses a gender identity that differs from the one that corresponds to the person's sex at birth.

Coding Instructions:

• Enter the appropriate code for the patient's gender using the table below.

- Code the natal sex (sex at birth) when known over transsexual or transgender, NOS.
- Code 3 when:
 - Intersexed (persons with sex chromosome abnormalities)
 - Hermaphrodite *Note:* Hermaphrodite is an outdated term.
- Code 4 for transsexuals/transgender/transgendered with unknown natal sex and primary site is **not** C510-C589 or C600-C639.
- Codes 5 and 6:
 - Have priority over codes 1 and 2.
 - \circ May be used for cases diagnosed prior to 2015.
- Code 5 for transsexuals who are natally male or transsexuals with primary site of C600-C639.
- Code 6 for transsexuals who are natally female or transsexuals with primary site of C510-C589.

When patient's gender is unknown:

- Code 1 when primary site is C600-C639.
- Code 2 when Primary site is C510-C589.
- Code 9 for primary sites not included above.
- The CCR requires documentation in <u>*Text* Remarks</u> to support the sex data item.

Code	Description
1	MALE
2	FEMALE
3	OTHER (intersex, disorders of sexual development/DSD). The word hermaphrodite formally classified under this code is an outdated term
4	TRANSEXUAL/TRANSGENDER/TRANSGENDERED, NOS
5	TRANSEXUAL/TRANSGENDER/TRANSGENDERED, natal male
6	TRANSEXUAL/TRANSGENDER/TRANSGENDERED, natal female
9	UNKNOWN

III.2.9 Religion

This data item captures the patient's religion or creed.

Coding Instructions:

- Enter the code for the patient's identified religion.
 - See <u>Appendix E Codes for Religions</u>.
- Code 99 if the religion is not stated.
- These codes and definitions were added for religion, effective with cases diagnosed January 1, 1998 and forward.
- Religion codes prior to 1998 were converted.

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III.2.10 Race and Ethnicity

Race and ethnicity are defined by specific physical, hereditary and cultural traditions, not necessarily by birthplace, place of residence, or citizenship. 'Origin' is defined by the Census Bureau as the heritage, nationality group, lineage, or in some cases, the country of birth of the person or the person's parents or ancestors before their arrival in the United States.

Beginning with cases diagnosed January 1, 2000, four race data items were added to the data set in addition to the existing race data item. These four data items were added so patients who belong to more than one racial category can be coded with multiple races, consistent with the 2000 Census. All resources in the facility, including the medical record, face-sheet, physician and nursing notes, and any other sources, must be used to determine race. If a facility does not print race in the medical record but does maintain it in electronic form, the electronic data must also be reviewed.

Sources:

- The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Race* data item.
- See <u>SPM-Appendix D Race and Nationality Descriptions</u> for guidance.
 - For the most updated list of the American Indian, Alaskan Indian, Aleut, and Eskimo and Tribes, please see the <u>Race Code list</u>, pages 6-31 as referenced in SPM-Appendix D, linked above.

Expectations on documenting race in text:

- Document supporting information in <u>*Text Remarks.</u>*</u>
- Cases with conflicting information, which lack supporting text documentation, will be returned as queries and counted as discrepancies.
 - Outlined below are examples of when text documentation would be required.
 - A text statement indicating patient's race, i.e., "Pt is Japanese," is required for conflicting types of cases. Such remarks must be entered in either the physical exam or remarks text data items.

Examples: These examples	amples are not intended to d	lemonstrate all possible scenarios.
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Scenarios Demonstrating Conflicting Race Information:
Name: June Hashimoto
Race: White
Birthplace: Unknown
Marital Status: Single
Name: Bob Nguyen
Race: White
Birthplace: Mexico
Name: Robert Jackson
Race: Mexican
Birthplace: California

Name: Moon Smith
Race: Japanese
Birthplace: California
Marital Status: Married
Name: Maria Tran
Race: White
Birthplace: Spain
Marital Status: Separated
Name: Carlos Johnson
Race: Black
Ethnicity: Hispanic
Birthplace: California

Standard Setter Differences:

CCR Exceptions to Standard Setter Coding Instructions.

- CCR Code 90 (highlighted in the code table below) Per 2004 SEER guidelines, races previously coded to 09 Asian Indian were to be coded to 96 Other Asian, including Asian, NOS. For consistency, the CCR created a new code, code 90 for Other South Asian that includes Bangladeshi, Bhutanese, Nepalese, Sikkimese, Sri Lankan (Ceylonese). Cases are converted from 90 to 96 for Calls for Data.
- Use of patient name in determining race:
 - Do not code race from name alone, especially for females with no surname (formerly known as maiden name) given.
 - In general, a name may be an indicator of a racial group, but should not be taken as the only indicator of race.
 - A patient name may be used to identify a more specific race code.
 - A patient name may be used to infer Spanish ethnicity or place of birth, but a Spanish name alone (without a statement about race or place of birth) cannot be used to determine the race code.
- Photographs of patients may be used but **only** with <u>extreme caution</u>. Photographs are often misleading and unreliable.
 - Use this source only when all other options are exhausted and there is no conflicting information.
 - If a photograph is used, documentation **must** be present in $\underline{Text Remarks}$ explaining the use of the photograph.

III.2.10.1 Codes for Race Data Item

Enter the most appropriate code for a patient's race(s) or ethnicity. See <u>*Race and Ethnicity*</u> for coding instructions. CCR-specific code(s) are highlighted in the table for clarification.

Code	Description
01	WHITE
02	BLACK OR AFRICAN AMERICAN
03	AMERICAN INDIAN, ALASKA NATIVE (includes all indigenous populations of the Western Hemisphere)
04	CHINESE
05	JAPANESE
06	FILIPINO
07	NATIVE HAWAIIAN
08	KOREAN
10	VIETNAMESE
11	LAOTIAN
12	HMONG
13	CAMBODIAN

	
14	THAI
15	ASIAN INDIAN, NOS OR PAKISTANI, NOS
16	ASIAN INDIAN
17	PAKISTANI
20	MICRONESIAN, NOS
21	CHAMORRO
22	GUAMANIAN, NOS
25	POLYNESIAN, NOS
26	TAHITIAN
27	SAMOAN
28	TONGAN
30	MELANESIAN, NOS
31	FIJI ISLANDER
32	PAPUA NEW GUINEAN
88	NO ADDITIONAL RACES (Race 2-5)
90	OTHER SOUTH ASIAN, INCLUDING BANGLADESHI, BHUTANESE, NEPALESE, SIKKIMESE, SRI LANKAN (CEYLONESE)
96	OTHER ASIAN, INCLUDING ASIAN, NOS
97	PACIFIC ISLANDER, NOS
98	SOME OTHER RACE
99	UNKNOWN BY PATIENT

III.2.10.2 Spanish/Hispanic Origin

This data item is used to identify patients with Spanish/Hispanic surname or of Spanish origin. Persons of Spanish or Hispanic surname/origin may be of any race.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Spanish/Hispanic Origin* data item.

CCR Guideline:

• Refer to <u>Appendix D - Spanish Surnames</u> for the list of Spanish Surnames for the CCR.

III.2.11 Date of Birth

This data item captures the month, day, and year of the patient's birth.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Date of Birth* data item.

III.2.12 Age at Diagnosis

This data item captures the age of the patient at the time of **diagnosis for this cancer or tumor.** This data item is tumor specific. A patient may be a different age for each tumor diagnosis.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Age at Diagnosis* data item.

III.2.13 Birthplace - Country

The *Birthplace* - *Country* data item is intended to collect information on the patient's country of birth.

Source: The <u>SPM-Appendix B - Country and State Codes</u> is to be used for coding the Birthplace-Country data item.

III.2.13.1 Birthplace - State

Birthplace - State is a two-digit data item that is intended to collect information on the patient's birth state.

Source: The <u>SPM-Appendix B - Country and State Codes</u> is to be used for coding the *Birthplace-State* data item.

III.2.14 Occupation and Industry

Because the identification of occupational cancer is an important aspect of cancer research, every effort should be made to record the occupation and the industry in which the patient works or worked, regardless of whether the patient was employed at the time of admission.

Source: <u>A Cancer Registrar's Guide to Collecting Industry and Occupation</u> is to be used when coding Occupation and Industry data items.

Guidelines:

- Ideally, the information should pertain to the longest held job (other than housework performed in the patient's home).
- Review all admissions in the patient's medical record, including those before the diagnosis of cancer, and record the best information available. It is not necessary to request parts of the medical record predating diagnosis solely to determine occupation and industry, but review all admissions in the parts pulled for abstracting.
- Good sources of information include admission and discharge summaries, face sheets, history and physical examination reports, oncology consultation reports, and health and social history questionnaires the patient has completed.
- The CCR will code the occupation and industry using the United States Bureau of the Census occupation and industry classifications.

III.2.14.1 Occupation

The usual (longest-held) occupation and industry of workers can reveal the national cancer burden by industry and occupation. Such information can also be used to help discover jobs that may have a high risk for cancer or other diseases and for which prevention efforts can be concentrated (or targeted).

Coding Instructions:

- Enter any available information about the kind of work performed (e.g., television repairman, chemistry teacher, bookkeeper, construction worker) associated with the longest held occupation. This data item may contain up to 100 characters.
- Avoid the use of abbreviations where possible.
- If the patient is not employed, try to determine the longest held occupation.
- Do not enter a term such as "homemaker", "student", "retired", "unemployed", or "disabled" unless no other information can be obtained.
- If no information is available, enter "NR" (not recorded). Do not leave this data item blank.

III.2.14.2 Industry

The usual (longest-held) occupation and industry of workers can reveal the national cancer burden by industry and occupation. Such information can also be used to help discover jobs that may have a high risk for cancer or other diseases and for which prevention efforts can be concentrated (or targeted).

Coding Instructions:

- Enter any available information about the industry associated with the longest held occupation (e.g., automotive repair, junior high school, trucking, house construction), up to 100 characters.
- If the chart identifies the employer's name but does not describe the industry, enter the employer's name (and city if available).
- If only an abbreviation is given for the industry or employer (e.g., PERS, USD, or FDIC), record it even if it's meaning is not known (avoid the use of abbreviations where possible).
- If no information is available, enter "NR" (not recorded). Do not leave this data item blank.

III.2.14.3 Occupation and Industry - Children

Occupation and Industry specific information is required to be entered in the abstract for children as well as adults. Follow the instructions below for Occupation and Industry if the patient is under 18 years of age.

Coding Instructions:

- Enter "Child" in the *Occupation* data item when the patient is a child.
 - This data item is left justified.
- Record any information available about the occupations of the parents and the industries in which they are employed.
- Record the occupation and industry of both parents if the information is in the medical record.

- If there is not enough room, however, give priority to the father's occupation and industry.
- Precede information about a parent with "FA" (father) or "MO" (mother).

1. Patient is 10 years old. Father is a field engineer with an oil company. Mother is an artist (NOS). Complete the *Occupation and Industry* data items as follows:

Occupation: Child - FA: field engineer MO: artist Industry: FA: oil industry

2. Patient is 14 years old. Father's occupation is not recorded. Mother is a biology professor at a university. Complete the *Occupation and Industry* data items as follows:

Occupation: Child - MO: biology professor Industry: MO: University

III.2.15 No Patient Contact Flag

The *No Patient Contact Flag* data item is to be set to code 0 or 1 if there is documentation on the medical record or if the cancer registry has been contacted by the patient, family member, or the patient's physician saying that they do not want to be included in research studies.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for *No Patient Contact Flag* data item.

III.2.16 Height

Document the patient's height in this data item. This data item is required if available by the CCR (if the information is obtainable for abstracting, it is required) for cases diagnosed January 1, 2011 and forward.

Coding Instructions:

- Different tumors for the same patient may have different values.
- The patient's height should be collected from source records once for each cancer.
- Height should be taken from the Nursing Interview Guide, Flow Chart, or Vital Stats section from the patient's reporting facility medical record or physician office record.
- The height entered should be that listed at or around the time of diagnosis.
- If no height was listed on the date of diagnosis, please use the height recorded on the date closest to the date of diagnosis and before treatment was started.
- Entered as 2-digit number and measured in inches (note that 1 foot=12 inches).

Example: Patient is stated to be 6 feet 1 inch (6`1") tall. Enter 73 into this data item.

- Code 98 for 98 inches or greater.
- Code 99 for unknown height.

- All inches' values should be rounded to the nearest whole number; values with decimal place x .5 and greater should be rounded up (e.g., 62.5 inches would be 63 inches).
- Exhaust all potential sources for height before using code 99 (unknown).
- Leaving this data item blank is not permitted and code 99 should be used to reflect unknown height. The CDC will use the volume of cases coded to 99 to help determine the availability of information related to height in the medical record.
- Use the Height Conversion Table below to convert to inches:

Feet (ft)	Inches (in)	Centimeters (cm)
1' 6"	18"	46
1' 7"	19"	48
1' 8"	20"	51
1' 9"	21"	53
1' 10"	22"	56
1' 11"	23"	58
2'	24"	61
2' 1"	25"	64
2' 2"	26"	66
2' 3"	27"	69
2' 4"	28"	71
2' 5"	29"	74
2' 6"	30"	76
2' 7"	31"	79
2' 8"	32"	81
2' 9"	33"	84
2' 10"	34"	86
2' 11"	35"	89
3'	36"	91
3' 1"	37"	94
3' 2"	38"	97
3' 3"	39"	99
3' 4"	40"	102
3' 5"	41"	104
3' 6"	42"	107

Height Conversion Table

on Table		
3' 7"	43"	109
3' 8"	44"	112
3' 9"	45"	114
3' 10"	46"	117
3' 11"	47"	119
4'	48"	122
4' 1"	49"	124
4' 2"	50"	127
4' 3"	51"	130
4' 4"	52"	132
4' 5"	53"	135
4' 6"	54"	137
4' 7"	55"	140
4' 8"	56"	142
4' 9"	57"	145
4' 10"	58"	147
4' 11"	59"	150
5'	60"	152
5' 1"	61"	155
5' 2"	62"	157
5' 3"	63"	160
5' 4"	64"	163
5' 5"	65"	165
5' 6"	66"	168
5' 7"	67"	170
5' 8"	68"	173
5' 9"	69"	175
5' 10"	70"	178

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5' 11"	71"	180
6'	72"	183
6' 1"	73"	185
6' 2"	74"	188
6' 3"	75"	191

6' 4"	76"	193
6' 5"	77"	195
6' 6"	78"	198
6' 7"	79"	201
6' 8"	80"	203

III.2.17 Weight

Document the patient's weight at diagnosis in this data item. This data item is required if available by the CCR (if the information is obtainable for abstracting, it is required) for cases diagnosed January 1, 2011 and forward.

Guidelines:

- Different tumors for the same patient may have different values.
- The patient's weight should be collected from source records once for each cancer.
- Weight should be taken from the Nursing Interview Guide, Flow Chart, or Vital Stats section from the patient's reporting facility medical record or physician office record.
- The weight entered should be that listed on the date of diagnosis.

Coding Instructions:

• Entered as 3-digit numbers and measured in pounds (note that 1 kg = 2.2 pounds).

Example: Patient is documented as 195. Enter 195 into this data item.

- Code 999 for unknown weight.
- All pound values should be rounded to the nearest whole number; values with decimal place x.5 and greater should be rounded up (e.g., 155.5 pounds would be 156 pounds).
- Patients with a weight of less than 100 pounds should be recorded with a leading 0.
- Exhaust all potential sources for weight before using code 999 (unknown).
- Leaving this data item blank is not permitted and code 999 should be used to reflect unknown weight. The CDC will use the volume of cases coded to 999 to help determine the availability of information related to weight in the medical record.
- If no weight was listed on the date of diagnosis, please use the weight recorded on the date closest to the date of diagnosis and before treatment was started.
- Use the Weight Conversion Table below to convert to pounds:

Kilograms (kg)	Pounds (lb)
1	2
2	4

Weight Conversion Table

3	7
4	9
5	11

6	13
7	15
8	18

9	20
10	22
11	24
12	26
13	29
14	31
15	33
16	35
17	37
18	40
19	42
24	44
21	46
22	49
23	51
24	53
25	55
26	57
27	60
28	62
29	64
30	66
31	68
32	71
33	73
34	75
35	77
36	79
37	82
38	84
39	86
40	88
41	90
42	93
43	95
44	97
45	99

46	101
47	104
48	106
49	108
50	110
51	112
52	115
53	117
54	119
55	121
56	123
57	126
58	128
59	130
60	132
61	134
62	137
63	139
64	141
65	143
66	146
67	148
68	150
69	152
70	154
71	157
72	159
73	161
74	163
75	165
76	168
77	170
78	172
79	174
80	146
81	179
82	181

83	183
84	185
85	187
86	190
87	192
88	194
89	196
90	198
91	201
92	203
93	205
94	207
95	209
96	212
97	214
98	216
99	218
100	220
101	223
102	225
103	227
104	229
105	231
106	234
107	236
108	238
109	240
110	243
111	245
112	247
113	249
114	251
115	254
116	256
117	258
118	260
119	262

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121	267	138	304	155	342
122	269	139	306	156	344
123	271	140	309	157	346
124	273	141	311	158	348
125	276	142	313	159	351
126	278	143	315	160	353
127	280	144	317	161	355
128	282	145	320	162	357
129	284	146	322	163	359
130	287	147	324	164	362
131	259	148	326	165	364
132	291	149	328	166	366
133	293	150	331	167	368
134	295	151	333	168	370
135	298	152	335		
136	300	153	337		

III.2.18 Tobacco Use

Records the patient's past or current use of tobacco.

Standard Setter Differences:

- The *Tobacco Use Smoking Status* is a new data item introduced with the 2022 data changes. This data item is required if available by the CCR (if the information is obtainable for abstracting, it is required) for cases diagnosed January 1, 2022 and forward.
 - The information recorded in this data item is not comparable to the information that has been historically collected in the Tobacco Use data items under the CDC Comparative Effectiveness Research (CER) and Patient Centered Outcomes Research (PCOR) project.
 - However, in an effort to alleviate double collection of Tobacco Use by the registrars, the CCR has decided to eliminate collection of Tobacco Use Cigarette and Tobacco Use Other Smoke for cases diagnosed 2022+.
- The requirement revisions are:
 - The CCR will continue to require the two data items below, if available on cases diagnosed January 1, 2011 and forward.
 - 1. Tobacco Use Smokeless
 - 2. Tobacco Use NOS
 - The CCR will **only** require the two data items below, if available for cases diagnosed January 1, 2011 through December 31, 2021.
 - 1. Tobacco Use Cigarette

2. Tobacco Use Other Smoke

• The CCR requires documentation in <u>*Text*</u> - <u>*Remarks*</u> to support the Tobacco Use data items.

III.2.18.1 Tobacco Use Smokeless and Tobacco Use, NOS

Tobacco Use Smokeless and Tobacco Use, NOS are required if available by the CCR (if the information is obtainable for abstracting, it is required) for cases diagnosed January 1, 2011 and forward.

Coding Instructions:

- Tobacco use should be recorded from sections such as the Nursing Interview Guide, Flow Chart, Vital Stats or Nursing Assessment section, or other available source from the patient's reporting facility medical record or physician office record.
- Electronic cigarettes are **not** to be coded in this data item.
- *Tobacco Use Smokeless* is used to capture Smokeless tobacco products (e.g. chewing tobacco, snuff, etc.).
- *Tobacco Use, NOS* is used to capture tobacco use when there is no documentation in the medical record that indicates the type of tobacco product (smokeless, cigarettes, cigars, etc.).
- Code 0 if the medical record indicates "None," ("Never Used").
- Code 9 (Unknown/not stated/no smoking specifics provided) if the medical record only indicates "No," rather than "Never used."
- The CDC will use the volume of cases coded to "9" to help determine the availability of information related to tobacco use in the medical record.

Code	Description
0	NEVER USED
1	CURRENT SMOKER (i.e., "current user" as of date of diagnosis) (added July 2011)
2	FORMER SMOKER, quit within one year of the date of diagnosis
3	FORMER SMOKER, quit more than one year prior to the date of diagnosis
4	FORMER USER, unknown when quit
9	UNKNOWN/NOT STATED, no smoking specifics provided

III.2.18.2 Tobacco Use Smoking Status

This data item captures the patient's past or current use of tobacco (cigarette, cigar and/or pipe). This data item is required if available by the CCR (if the information is obtainable for abstracting, it is required) for cases diagnosed January 1, 2022 and forward.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Tobacco Use Smoking Status* data item.

III.3 Case Identification

While some of the data reported on the Case Identification screens are only for identification and document control, the date of diagnosis serves as the basis for computing incidence, survival, and other statistics. Accurate recording of the date of the first diagnosis of a reportable neoplasm is especially important.

III.3.1 Year First Seen

Year first seen is the year the patient was first seen for this reportable primary.

Coding Instructions:

• Enter the four-digit year during which the patient was first seen at the reporting facility for diagnosis or treatment of the neoplasm reported in this abstract. For patients seen at the end of the year, use the year of diagnosis as the year first seen for this primary.

Example: A patient is admitted to the reporting facility in December 2019 and is diagnosed in January 2020. Assign 2020 as the year first seen for this primary.

III.3.2 Abstracting - Accession and Sequence Number

Each patient in a reporting facility's cancer registry is identified by a permanent nine-digit accession number and each of the patient's primary tumors is identified by a different two-digit sequence number. The accession number remains the same in every abstract prepared by the reporting facility for the patient, but the sequence number is different for each new tumor.

Source: The <u>Standards for Oncology Registry Entry (STORE)Manual</u> is to be used for coding instructions and guidelines for the Accession Number and Sequence Number data items.

- Accession Number This data item identifies the patient and the tumor. Each patient entered in a reporting facility registry is assigned a unique accession number, and each primary diagnosed for that patient is assigned a sequence number. The accession number never changes and is never reassigned, even if a patient is removed from the registry. The accession number may be auto generated by some abstracting vendors.
- **Sequence Number** Sequence refers to the chronological position of a patient's primary tumor among all the reportable tumors occurring during the patient's lifetime, whether they exist at the same or separate times and whether or not they are entered in the reporting facility's registry.

III.3.3 Date of First Contact

Per SEER Clarification, effective January 1, 2012 and forward, date of first contact is the admission date when the patient was an inpatient or an outpatient at the reporting facility.

Source: The <u>Standards for Oncology Registry Entry (STORE)Manual</u> is to be used for coding instructions and guidelines for Date of First Contact data item.

III.3.4 Dates of Inpatient Admission and Inpatient Discharge

Enter the dates of Inpatient Admission and Inpatient Discharge to the reporting facility for the most definitive surgery.

See <u>Entering Dates</u> for additional information regarding entering dates. Consult with your software vendor for specific data entry instructions.

Coding Instructions:

- Use the inpatient admission and discharge dates for any other cancer-directed therapy when the patient does not have surgery.
- Use the dates of inpatient admission and discharge for diagnostic evaluation when the patient has not had cancer-directed therapy.

III.3.5 Date of Diagnosis

This data item captures the month day and year of the patient's diagnosis. It serves as the basis for computing incidence, survival, and other statistics. Accurate recording of the date of the first diagnosis of a reportable neoplasm is especially important.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Date of Diagnosis* data item.

See <u>*Reporting in California*</u> and <u>*CCR Reportability Guide - Reportable*</u> for CCR Specific Standard Setter Differences.

III.3.6 Place of Diagnosis

If the case was not first diagnosed at the reporting facility, enter whatever is known about the place of diagnosis:

Scenario	Instruction
ANOTHER REPORTING FACILITY	Enter the facility's name, the city, and the state
PHYSICIAN ONLY	Enter physician's name and address. If the physician is on the reporting facility's medical staff, also enter "Staff Physician"
REPORTING FACILITY AND PHYSICIAN UNKNOWN	Enter name of city, state, or country where diagnosis was first made
NO INFORMATION AVAILABLE	Enter "unknown"

III.3.7 Class of Case

Class of Case is divided into two basic categories: Analytic and Nonanalytic.

Definitions:

- Analytic cases (codes 00-22) are grouped according to the location of diagnosis and first course of treatment. Analytic cases are required to be reported to the CCR by all facilities. These cases are included in treatment and survival analyses.
- **Nonanalytic cases** include codes 30-49 and 99. The CCR requires that specific non-analytic cases be abstracted by the reporting facility.
 - Non-analytic class of cases which always require reporting to CCR via an abstract are 32, 34-38.
 - Non-analytic class of case 30 requires reporting to CCR via an abstract under most, but not all scenarios (see details below).

• Class of Case change from non-analytic to analytic:

Example: The patient had diagnoses elsewhere and comes to your facility for treatment planning only (Class 30) and the case is abstracted as Class 30. If a decision is made for the patient to receive all or part of first course of treatment at your facility, the case is now analytic (Class 20-22). The date of first contact is updated to the date when the case became analytic.

For specific reportability requirements, see *<u>Reporting in California</u>*.

A facility's Cancer Committee may also direct reporting of non-analytic cases. Nonanalytic cases are not required to be abstracted by the CoC and are not included in treatment and survival analyses.

Analytic Classes of Case

Initial Diagnosis at Reporting Facility

Code	Description
00	INITIAL DIAGNOSIS AT THE REPORTING FACILITY <u>AND</u> ALL TREATMENT OR DECISION NOT TO TREAT WAS DONE ELSEWHERE
	Example: Patient was diagnosed with squamous cell carcinoma of the tonsil by biopsy at reporting facility; underwent surgical resection at another facility.
	<i>Note:</i> Beginning in 2010, Class of Case 00 includes cases diagnosed by the facility that are treated in staff or non-staff physician' offices, as well as cases when it is known that the patient went elsewhere for treatment. Facility Referred To, MUST be documented.
	<i>Note:</i> Use Class of Case 10 if there is no information about whether or where the patient was treated.
	<i>Note:</i> Use Class of Case 14 if the patient received no treatment, either because the patient refused recommended treatment, or a decision was made not to treat.
	INITIAL DIAGNOSIS AT THE REPORTING FACILITY OR IN AN OFFICE OF A PHYSICIAN WITH ADMITTING PRIVILEGES <u>AND</u> PART OR ALL OF FIRST COURSE TREATMENT OR A DECISION NOT TO TREAT WAS AT THE REPORTING FACILITY, NOS
10	<i>Note:</i> Use Class of Case 10 if there is no information about whether or where the patient was treated.
	Example: Homeless patient is diagnosed by biopsy at reporting facility; facility was unable to discover whether the patient actually received any treatment elsewhere.
11	INITIAL DIAGNOSIS IN AN OFFICE OF A PHYSICICAN WITH ADMITTING PRIVILEGES <u>AND</u> PART OF FIRST COURSE TREATMENT WAS DONE AT THE REPORTING FACILIT
	Example: Patient was diagnosed by a physician with admitting privileges, received neoadjuvant radiation at another facility, and underwent surgical resection at the reporting facility.
12	INITIAL DIAGNOSIS IN AN OFFICE OF A PHYSICIAN WITH ADMITTING PRIVILEGES <u>AND</u> ALL FIRST COURSE TREATMENT OR A DECISION NOT TO TREAT WAS DONE AT THE REPORTING FACILITY
13	INITIAL DIAGNOSIS AND PART OF THE FIRST COURSE OF TREATMENT WAS DONE AT THE REPORTING FACILITY <u>AND</u> PART OF FIRST COURSE TREATMENT WAS DONE ELSEWHERE

	Example: Breast cancer was diagnosed and treated with surgery at the reporting facility. Radiation was given at the facility across the street with which the reporting facility has an agreement.
14	INITIAL DIAGNOSIS AT THE REPORTING FACILITY <u>AND</u> ALL FIRST COURSE TREATMENT OR A DECISION NOT TO TREAT WAS DONE AT THE REPORTING FACILITY
	<i>Note:</i> Use Class of Case 14 if the patient received no treatment, either because the patient refused recommended treatment, or a decision was made not to treat.

Initial Diagnosis Elsewhere, Facility Involved in First Course Therapy

Code	Description
20	INITIAL DIAGNOSIS ELSEWHERE <u>AND</u> PART OR ALL OF FIRST COURSE TREATMENT WAS DONE AT THE REPORTING FACILITY, NOS
21	INITIAL DIAGNOSIS ELSEWHERE <u>AND</u> PART OF FIRST COURE TREATMENT WAS DONE AT THE REPORTING FACILITY; PART OF THE FIRST COURSE TREATMENT WAS DONE ELSEWHERE Example: Definitive or repeat biopsy following initial FNA or biopsy performed elsewhere.
22	INITIAL DIAGNOSIS ELSEWHERE <u>AND</u> ALL FIRST COURSE TREATMENT OR A DECISION NOT TO TREAT WAS DONE AT THE REPORTING FACILITY

Non-Analytic Classes of Case

Patient Appears in Person at Reporting Facility; Both Initial Diagnosis and Treatment Elsewhere

Code	Description
	INITIAL DIAGNOSIS AND ALL FIRST COURSE TREATMENT ELSEWHERE <u>AND</u> REPORTING FACILITY PARTICIPATED IN DIAGNOSTIC WORKUP
	Examples: Consult Only; Treatment planning only; Staging workup after initial diagnosis elsewhere.
	Reporting <u>required</u> to CCR
30	Diagnostic/staging workup at the reporting facility after initial diagnosis elsewhere
50	Consult Only and facility is responsible for treatment decisions or follow-up.
	Reporting <u>NOT required</u> to CCR
	Consult Only and facility is <u>reviewing information only</u> to confirm a diagnosis made elsewhere, rendering a second opinion, or recommending treatment which will be done elsewhere.
	See Pathology and Consultation Only Cases for more information
31	INITIAL DIAGNOSIS AND ALL FIRST COURSE TREATMENT PROVIDED ELSEWHERE <u>AND</u> REPORTING FACILITY PROVIDED IN-TRANSIT CARE OR FACILITY PROVIDED CARE THAT FACILITATED TREATMENT ELSEWHERE
	<i>Examples:</i> Patient receiving transient care to avoid interrupting therapy initiated elsewhere (equipment failure at the reporting facility or while vacationing); Catheter placement for cancer therapy.
	Reporting <u>NOT required</u> to CCR

Diagnosis AND all first course treatment provided elsewhere AND patient presents at reporting facility with disease recurrence or persistence
Examples: Patient with active disease admitted for other medical condition(s); Patient expires in the ER with lung metastases; After treatment failure, patient is admitted for supportive care.
Reporting required to CCR
DIAGNOSIS <u>AND</u> ALL FIRST COURSE TREATMENT PROVIDED ELSEWHERE <u>AND</u> PATIENT PRESENTS AT REPORTING FACIILTY WITH DISEASE HISTORY ONLY.
Example: A patient admitted that does not have active disease.
Reporting <u>NOT required</u> to CCR
APPLICABLE TO COC-ACCREDITED FACILITIES <u>ONLY</u> . TYPE OF CASE NOT REQUIRED BY THE COC TO BE ACCESSIONED <u>AND</u> INITIAL DIAGNOSIS <u>AND</u> PART OR ALL OF FIRST COURSE TREATMENT BY REPORTING FACILITY. NON COC-ACCREDITED FACILITIES REPORT THESE AS ANALYTIC CASES Reporting required to CCR in this category include: Benign and borderline intracranial/CNS tumors diagnosed 1/1/2001 - 12/31/2003 only
<i>Note:</i> For cases diagnosed on or after 1/1/04 when these diagnoses became nationally reportable, use Class of Case codes 00-22.
Intraepithelial neoplasia grade II and III tumors as follows:
Anal intraepithelial neoplasia grade II (AIN II), dx 01/01/2022+
Anus (AIN III) cases, dx 01/01/2001+
Vaginal intraepithelial neoplasia grade II (VAIN II) dx 01/01/2022+
Vagina (VAIN III) cases, dx 01/01/1992+
Vulvar intraepithelial neoplasia grade II (VIN II), dx 01/01/2022+
Vulva (VIN III) cases, dx 01/01/1992+
Borderline ovarian tumors diagnosed 1/1/2001 through 12/31/2015
<i>Note:</i> Effective 1/1/2010, active follow-up is no longer required for borderline ovarian cases diagnosed 1/1/2001 forward.
CASES DIAGNOSED BEFORE PROGRAM'S REFERENCE DATE <u>AND</u> INITIAL DIAGNOSIS <u>AND</u> PART OR ALL OF FIRST COURSE TREATMENT BY REPORTING FACILITY
Reporting <u>required</u> to CCR for cases diagnosed on or after 1/1/1988, or the regional registry reference date if earlier. See <u>Reporting</u> for additional instructions.
APPLICABLE TO COC-ACCREDITED FACILITIES <u>ONLY</u> . TYPE OF CASE NOT REQUIRED BY THE COC TO BE ACCESSIONED <u>AND</u> INITIAL DIAGNOSIS ELSEWEHERE <u>AND</u> PART OR ALL OF FIRST COURSE TREATMENT BY REPROTING FACILITY. NON COC-ACCREDITED FACILITIES REPORT THESE AS ANALYTIC CASES
<i>Reporting <u>required</u> to CCR</i> in this category include:
Benign and borderline intracranial/CNS tumors diagnosed 1/1/2001 - 12/31/2003 only
<i>Note:</i> For cases diagnosed on or after 1/1/04 when these diagnoses became nationally reportable, use Class of Case codes 00-22.
Intraepithelial neoplasia grade II and III tumors as follows:
Anal intraepithelial neoplasia grade II (AIN II), dx 01/01/2022+

	Anus (AIN III) cases, dx 01/01/2001+
	Vaginal intraepithelial neoplasia grade II (VAIN II), dx 01/01/2022+
	Vagina (VAIN III) cases, dx 01/01/1992+
	Vulvar intraepithelial neoplasia grade II (VIN II), dx 01/01/2022+
	Vulva (VIN III) cases, dx 01/01/1992+
	Borderline ovarian tumors diagnosed 1/1/2001 through 12/31/2015
	<i>Note:</i> Effective 1/1/2010, active follow-up is no longer required for borderline ovarian cases diagnosed 1/1/2001 forward.
37	CASE DIAGNOSED BEFORE PROGRAM'S REFERENCE DATE <u>AND</u> INITIAL DIAGNOSIS ELSEWHERE <u>AND</u> PART OR ALL OF FIRST COURSE TREATMENT BY REPORTING FACILITY
	Reporting <u>required</u> to CCR for cases diagnosed on or after 1/1/1988, or the regional registry reference date if earlier. See <u>Reporting in California</u> for additional instructions.
38	INITIAL DIAGNOSIS ESTABLISHED BY AUTOPSY AT THE REPORTING FACILITY, CANCER NOT SUSPECTED PROIR TO DEATH
	Reporting <u>required</u> to CCR
	<i>Note:</i> If the patient is suspected to have a malignancy, confirmed at autopsy, code to Class of Case 14.

Patient Does Not Appear in Person at Reporting Facility

Code	Description	
40	DIAGNOSIS <u>AND</u> ALL FIRST COURSE TREATMENT GIVEN AT THE SAME PHYSICIAN'S* OFFICE	
41	DIAGNOSIS <u>AND</u> ALL FIRST COURSE TREATEMENT GIVEN IN TWO OR MORE DIFFERENT OFFICES OF PHYSICIANS WITH ADMMITTING PRIVILEGES	
42	NON-STAFF PHYSICIAN, CLINIC OR THER FACILITY, NOT PART OF REPORTING FACILITY, ACCESSIONED BY REPORTING FACILITY FOR DIAGNOSIS AND/OR TREATMENT BY THAT ENTITY	
	Example: Reporting facility abstracts cases from an independent radiation facility. PATHOLOGY OR OTHER LAB SPECIMENS ONLY	
43	Note: If a pathology specimen is submitted by a physician's office to be read at the reporting facility, notification to the regional registry is required. Class 43 is to be Used by CCR/Regional registries only.	
	DEATH CERTIFICATE ONLY	
49	Class 49 is to be Used by CCR/ Regional registries only.	

Unknown Relationship to Reporting Facility

Code	Description	
99	NONANALYTIC CASE OF UNKNOWN RELATIONSHIP TO FACILITY	
N A . CC 1 .		

* A staff physician is a physician who is employed by the reporting facility, under contract with it, or a physician who has routine practice privileges there.

III.3.8 Type of Reporting Source

Type of Reporting Source data item records the source documents used to abstract the majority of information on the tumor being reported.

Coding Instructions:

- Surgery for primary cancer performed at a hospital as an outpatient (no overnight stay). Assign code 1 if the hospital is part of a managed health plan with comprehensive, unified medical records meaning that a single record is maintained for each patient and that record includes all encounters in affiliated locations. Otherwise, assign code 8.
- Codes 3, 6 and 7 are only used with the following <u>*Class of Case*</u> codes:
 - Class 43 (Path Only) code 3
 - Class 38 (Autopsy Only) code 6
 - Class 49 (Death Certificate Only) code 7
- Codes 4 and 5 must be used with the following reporting facilities:
 - 0000999996, 000000803 or specific Physician# code 4
 - 0000000804 or specific Nursing Home# code 5
- Codes are arranged in the order of the precedence of the sources, with a hospital record first.
- Code this data item in the following priority order: 1, 2, 8, 4, 3, 5, 6, and 7.
- Enter code 1 for reporting source and code 2, for type of admission for Class 40 and 41 cases.

Code	Description	
1	HOSPITAL INPATIENT/Managed health plans with comprehensive, unified medical records	
2	RADIATION TREATMENT CENTERS OR MEDICAL ONCOLOGY CENTERS (HOSPITAL-AFFILIATED OR INDEPENDENT)	
3	LABORATORY, hospital or private (e.g., pathology specimen only)	
4	PRIVATE MEDICAL PRACTITIONER	
5	NURSING HOME, CONVALESCENT HOSPITAL, OR HOSPICE	
6	AUTOPSY ONLY (neoplasm discovered and diagnosed for the first time as a result of an autopsy - see <u>Class of Case</u>)	
7	DEATH CERTIFICATE ONLY (DCO)	
8	OTHER HOSPITAL OUTPATIENT UNITS/SURGERY CENTERS	

III.3.9 Type of Admission

This data item represents the type(s) of admission the patient had at the reporting facility.

Code	Description	
1	INPATIENT ONLY	
2	OUTPATIENT ONLY	
3 *	TUMOR BOARD ONLY	
4 *	PATHOLOGY SPECIMEN ONLY	

INPATIENT AND OUTPATIENT	
NPATIENT AND TUMOR BOARD	
OUTPATIENT AND TUMOR BOARD	
INPATIENT, OUTPATIENT, AND TUMOR BOARD	
UNKNOWN (may appear in archival files but is not entered by hospitals)	

* See <u>Reporting in California</u>, Required Method of Reporting Guide

III.3.10 Casefinding Source

This two-digit data item indicates the source that identified the case.

Coding Instructions:

- Determine where the case was first identified, and enter the appropriate code. However, if a hospital and a non-hospital source identified the case independently of each other, enter the code for the non-hospital source (i.e., codes 30-95 have priority over codes 10-29).
- If the case was first identified at a cancer reporting facility (codes 10-29), code the earliest source of identifying information.
- If a death certificate, private pathology laboratory report, consultation only report from a hospital, or other report was used to identify a case that was then abstracted from a different source, enter the code for the source that first identified the case, **not the source from which it was abstracted**.
- If the regional registry or CCR identifies a case and asks a reporting facility to abstract it, the regional registry or CCR **must** specify the appropriate code to be used in the data item.
- If a case was identified through the Death Clearance process at the regional registry, the hospital **must** use code 80 when abstracting the case.

Code	Description	
10	REPORTING HOSPITAL, NOS	
20	PATHOLOGY DEPARTMENT REVIEW (surgical pathology reports, autopsies, or cytology reports)	
21	DAILY DISCHARGE REVIEW (daily screening of charts of discharged patients in the medical records department)	
22	DISEASE INDEX REVIEW (review of disease index in the medical records department)	
23	RADIATION THERAPY DEPARTMENT/CENTER	
24	LABORATORY REPORTS (other than pathology reports, code 20)	
25	OUTPATIENT CHEMOTHERAPY	
26	DIAGNOSTIC IMAGING/RADIOLOGY (other than radiation therapy, code 23; includes nuclear medicine)	
27	TUMOR BOARD	
28	HOSPITAL REHABILITATION SERVICE OR CLINIC	

Case First Identified at Cancer Reporting Facility

29	OTHER HOSPITAL SOURCE (including clinic, NOS or outpatient department, NOS)
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Case First Identified by Source Other than a Cancer Reporting Facility

Code	Description	
30	PHYSICIAN INITIATED CASE	
40	CONSULTATION ONLY OR PATHOLOGY ONLY REPORT (not abstracted by reporting hospital)	
50	PRIVATE PATHOLOGY LABORATORY REPORT	
60	NURSING HOME INITIATED CASE	
70	CORONER'S OFFICE RECORDS REVIEW	
75	MANAGED CARE ORGANIZATION (MCO) OR INSURANCE RECORDS	
80	DEATH CERTIFICATE FOLLOW BACK (case identified through death clearance)	
85	OUT-OF-STATE CASE SHARING	
90	OTHER NON-REPORTING HOSPITAL SOURCE	
95	QUALITY CONTROL REVIEW (case initially identified through quality control activities of a regional registry or the CCR)	
99	UNKNOWN	

III.3.11 Payment Source (Primary and Secondary) and Payment Source Text

These data items identify the patient's insurance status at the time of initial diagnosis. It consists of three data items: *Primary Source of Payment, Secondary Source of Payment, and Payment Source Text.*

Standard Setter Differences:

CCR Exceptions to Standard Setter Coding Instructions:

• CCR Codes 28, 29, and 89 (highlighted in the code table below) are specific to California.

Coding Instructions:

- The primary payment source and text data items are required and may not be left blank.
- Record the primary payer from the information available at diagnosis.
- Enter the secondary payment source if it is available in the medical record.
- When multiple insurances are listed:
 - \circ Code the first mentioned as the primary, and the second as secondary.
 - Code the closest to the date of diagnosis when there are multiple admissions and/or multiple physician encounters.
- When the primary payer at diagnosis is unknown, record the information available during the initial treatment period.

- Code 02 when the only information is "self-pay."
- Code 10 for prisoners when no further information is available.
- Codes 28-HMO and 29-PPO are California specific codes that are converted to code 20-Managed Care for submission to standard setting agencies. This was effective with 2004 cases.
- Code 89-County Funded, NOS is a California specific code that is converted to code 31-Medicaid for submission to standard setting agencies. This was effective with 2006 cases.

Code	Label	Definition
01	NOT INSURED	Patient has no insurance and is declared a charity write- of
02	NOT INSURED, SELF PAY	Patient has no insurance and is declared responsible for charges
10	INSURANCE, NOS	Type of insurance unknown or other than the types listed in codes 20, 21, 31, 35, 60-68
20	PRIVATE INSURANCE: MANAGED CARE, HMO, OR PPO	An organized system of prepaid care for a group of enrollees usually within a defined geographic area. Generally formed as one of four types: a group model, an independent physician association (IPA), a network, or a staff model. "Gate-keeper model" is another term for describing this type of insurance
21	PRIVATE INSURANCE: FEE-FOR SERVICE	An insurance plan that does not have a negotiated fee structure with the participating reporting facility. Type of insurance plan not coded as 20
28	НМО	California specific code
29	РРО	California specific code
31	MEDICAID	State government administered insurance for persons who are uninsured, below the poverty level, or covered under entitlement programs. Medicaid other than described in code 35
35	MEDICAID ADMINISTERED THROUGH A MANAGED CARE PLAN	Patient is enrolled in Medicaid through a Managed Care program (for example, HMO or PPO). The Managed Care plan pays for all incurred costs
60	MEDICARE WITHOUT SUPPLEMENT, MEDICARE, NOS	Federal government funded insurance for persons who are 65 years of age or older, or are chronically disabled (Social Security insurance eligible), or are dialysis patients. Not described in codes 61, 62, or 63
61	MEDICARE WITH SUPPLEMENT, NOS	Patient has Medicare and another type of unspecified insurance to pay costs not covered by Medicare
62	MEDICARE - ADMINISTERED THROUGH A MANAGED	Patient is enrolled in Medicare through a Managed Care plan (for example, HMO or PPO). The Managed Care plan pays for all incurred costs

	CARE PLAN	
63	MEDICARE WITH PRIVATE SUPPLEMENT	Patient has Medicare and private insurance to pay costs not covered by Medicare
64	MEDICARE WITH MEDICAID ELIGIBILITY	Federal government Medicare insurance with State Medicaid administered supplement
65	TRICARE	Department of Defense program providing supplementary civilian-sector reporting facility and medical services beyond a military treatment facility to military dependents, retirees, and their dependents Formally CHAMPUS (Civilian Health and Medical Program of the Uniformed Services)
66	MILITARY	Military personnel or their dependents who are treated at a military facility
67	VETERANS AFFAIRS	Veterans who are treated in Veterans Affairs facilities
68	INDIAN/PUBLIC HEALTH SERVICES	Patient who receives care at an Indian Health Service facility or at another facility, and the medical costs are reimbursed by the Indian Health Service Patient receives care at a Public Health Service facility or at another facility, and medical costs are reimbursed by the Public Health Service
89	COUNTY FUNDED, NOS	California specific code
99	INSURANCE STATUS UNKNOWN	It is unknown from the patient's medical record whether or not the patient is insured

III.3.12 Reporting Facility Referred From and Referred To

The CCR assigned reporting facility code for the facility or agency that has referred the patient to your facility or agency that your reporting facility has referred the patient to.

Coding Instructions:

- Refer to the most current <u>California Reporting Facility Codes</u> lists, located on the CCR website <u>https://www.ccrcal.org</u>, Registrar Resources, Reporting Cancer in California, Volumes I-V.
 - Lists are presented in both alphabetical and code order.
- Code *Facility Referred From* to 0000999994 UNSPEC NONCAL HOSP, when out of state patient is seen at your facility for further workup or treatment.
- If the diagnosis was made before admission (diagnosed PTA), enter the CCR assigned reporting facility code for the other facility at which the patient was previously seen for the disease.

• If the patient is seen at another reporting facility or other facility for specialized cancer treatment or any other cancer-related reason after admission to the reporting facility, enter the facility's name or CCR assigned reporting facility code.

III.3.13 Physicians

Each reporting facility must maintain its own roster of physicians and their code or NPI numbers. The non-NPI numbers codes are based on the physicians' California license numbers.

As physicians who treat cancer patients join the reporting facility's staff, they must be added to the roster with their license or NPI numbers. If the license number is unavailable, assign a temporary number, beginning it with the letter X to differentiate it from regular codes. When the license number becomes available, update the files as soon as possible.

III.3.13.1 Physician License Numbers

Enter the physician's license number.

Coding Instructions:

- Enter the California State **<u>physician's</u>** license number.
 - These are eight characters in length and the first character is always an alpha character.
 - License numbers less than eight characters insert zero(s) after the first alpha character.

Example: Physician - A23456 would be entered A0023456

• For <u>dentists</u>, the same instructions apply.

Example: Dentist - D00056789 would be entered D0056789

- For <u>osteopaths</u>, add a leading O (alpha character) and then enter the entire eight-character code.
 - It is important to note that the first character of the osteopath license is an alpha character, and the third character is a zero.
 - For handling a nine-character number, drop the first zero after O2.

Example: Osteopath - O20A4422 would be entered O20A4422 or for nine-digit O20A44222 would be entered O2A44222

- Out-of-state license numbers:
 - The first character must be an X.
 - If this number is less than seven characters, insert zeros between the X and the license number.

III.3.13.2 Entering Physician NPI Codes

The National Provider Identifier (NPI) is a unique identification number for health care providers. It is scheduled for 2007 implementation by the Centers for Medicare and Medicaid Services (CMS) as part of the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Health care providers have started the process of obtaining NPI codes, and hospitals have until May 2007 to meet the HIPAA deadline. NPI numbers are being distributed by CMS to all health care providers in the United States. CMS has mandated use of the assigned NPI in all administrative and financial transactions between "large" health plans and CMS starting in May 2007. For billing purposes, these providers will be required to use NPI codes by May 2007, but indications are that some health care facilities will start

using these codes in advance of this deadline. If a facility starts to use the NPI codes, that information should be available from the provider's billing department.

NPI numbers are only assigned to health care providers who meet the definition of a "covered entity," and this only includes individuals and entities licensed to provide health care. NPI's are not being issued to physicians who have opted out of government programs; entities that bill or are paid for health care services furnished by other health care providers; or clearing houses, vendors, administrative, and billing services (*Federal Register* [Friday, January 23, 2004]).

Registries should be able to record the NPI for their hospital or individual physicians with January 1, 2007, diagnoses. It is necessary, however, to be aware that NPI's may not have been assigned to all eligible parties by January 1, 2007. Historic facilities or physicians may no longer be in business or licensed and therefore, may not have an NPI assigned.

NAACCR Fields that use NPI

- **NPI--Registry ID** stores the NPI of the facility registry that transmits the record.
- **NPI--Reporting Facility** The NPI code for the facility submitting the data in the record.
- **NPI--Inst Referred From** The NPI code that identifies the facility that referred the patient to the reporting facility.
- **NPI--Inst Referred To** The NPI code that identifies the facility to which the patient was referred for further care after discharge from the reporting facility.
- **NPI--Following Registry** The NPI code that records the registry responsible for following the patient.
- **NPI--Physician--Managing** The NPI code that identifies the physician who is responsible for the overall management of the patient during diagnosis and/or treatment for this cancer.
- **NPI--Physician--Follow-Up** The NPI code for the physician currently responsible for the patient's medical care.
- **NPI--Physician--Primary Surg** The NPI code for physician who performed the most definitive surgical procedure.
- NPI--Physician 3 The NPI code for another physician involved in the care of the patient.
- **NPI--Physician 4** The NPI code for another physician involved in the care of the patient.

Coding Instructions:

- The *Managing Physician* data item may not be blank.
- Record the 10-digit NPI for the surgeon, radiation oncologist, and/or medical oncologist.
- Additional physicians are designated by their role in the case, i.e. referring, consulting, and other. See *Follow-Up Physician* for further instructions.
- If there is no physician, or the physician cannot be determined, leave blank.
- If the managing physician is the same as another physician, (i.e., the medical oncologist) the NPI number must be entered in both places.
- Do not update this item. Once the registry has designated a managing physician, radiation oncologist, and/or medical oncologist for the patient, the information should not be changed or updated even if the patient receives care from another physician.
- NPI may be left blank if diagnosed before January 1, 2007.

Code	Description
(fill spaces)	10-digit NPI number
BLANK	No physician, physician cannot be determined

III.3.14 Comorbidities and Complications/Secondary Diagnosis

Records the patient's preexisting medical conditions, factors influencing health status, and/or complications during the patient's hospital stay for the treatment of this cancer using ICD-9-CM codes. All are considered secondary diagnoses.

Source: The <u>Standards for Oncology Registry Entry (STORE)Manual</u> is to be used for coding instructions and guidelines for Comorbidities and Complications/Secondary Diagnosis data items.

Comorbidities and Complications

Comorbidities and Complications 1-10 data items are designated to capture the patient's preexisting medical conditions, factors influencing health status, and/or complications during the patient's admission to the reporting facility for the treatment of the cancer using ICD-9-CM codes. These factors may affect treatment decisions and influence outcomes. Data collection of *Comorbidities and Complications 1-10* data items are required if available by the CCR (if the information is obtainable for abstracting, it is required), and is required from CoC facilities. This requirement applies to cases diagnosed between January 1, 2004 and December 31, 2014.

Secondary Diagnosis 1-10

Secondary Diagnosis 1-10 data items are designed to capture the patient's preexisting or secondary diagnosis, factors influencing health status, and/or complications during the admission to the reporting facility for the treatment of cancer using ICD-10-CM codes. These factors may affect treatment decisions and influence outcomes. These data items were developed to capture ICD-10-CM, which can be up to 7 characters in length and have a different structure than ICD-9-CM. **ICD-10-CM were implemented October 1, 2015.** Data collection of Secondary Diagnosis 1-10 data items are required if available by the CCR (if the information is obtainable for abstracting, it is required), and is required from CoC facilities.

III.3.14.1 ICD Revision - Comorbidities and Complications

This item indicates the coding system from which the *Comorbidities and Complications* codes are provided. This data item is not required by the CCR, but it is required for CoC approved facilities. *ICD Revision Comorbidities and Complications* are to be recorded for patients diagnosed January 1, 2006 and forward.

Source: The <u>Standards for Oncology Registry Entry (STORE)Manual</u> is to be used for coding instructions and guidelines for ICD Revision-Comorbidities and Complications data item.

III.3.14.2 Source Comorbidity

This CCR Specific data item is intended to record the data source from which comorbidities/ complications was collected. It is required by the CCR for cases diagnosed January 1, 2011 and forward.

Note: Source Comorbidity does not include data sources reflecting Secondary Diagnosis.

Coding Instructions:

• If comorbidities/complications are coded, then the source comorbidity data item must be coded.

Code	Description
0	NO COMORBID CONDITION OR COMPLICATION IDENTIFIED / NOT APPLICABLE
1	COLLECTED FROM FACILITY FACE SHEET

III.3.15 Discovered by Screening

This data item tracks which cancer cases were first diagnosed via screening programs. This item is required if available by the CCR (if the information is obtainable for abstracting, it is required).

Coding Instructions:

- If this information is not available, the data item may be left blank.
- It is an existing optional data item as part of the Department of Defense Data Set and will be collected and transmitted from facilities completing the Department of Defense Data Set.

Code	Description
0	NO (discovered by some other method such as symptomatic patient)
1	ROUTINE SCREENING EXAM (e.g. routine screening mammogram in asymptomatic patient)
2	REPORTING FACILITY SCREENING PROGRAM (targeted to a particular cancer)
3	STATE-SPONSORED SCREENING PROGRAM
4	NATIONALLY SPONSORED SCREENING PROGRAM
5	OTHER TYPE OF SCREENING (e.g., American Cancer Society screening project)
9	UNKNOWN IF VIA SCREENING (default)

Part IV. Text Documentation

Part IV of Volume I provides instructions for recording information in text fields on the abstract. Text documentation is an essential component of a complete electronic abstract and is heavily utilized for quality control and special studies. Text is needed to justify coded values and to document supplemental information not transmitted within coded values. High-quality text documentation facilitates consolidation of information from multiple reporting sources at the central registry.

Guidelines:

- Coded data items **must** be supported by text documentation on the abstract, with the following exceptions:
 - Date of Birth (DOB) (unless the patient is 100 years of age or older) See <u>Age at</u> <u>Diagnosis</u>.
 - Social Security Number (SSN)
 - Medical Record Number (MRN)
 - \circ Comorbidities
 - Secondary Diagnosis

- For additional information on topics listed in this section, please refer to <u>Appendix H Q-Tips</u>, for a list of topics.
- CCR Q-Tips are available in the CCR learning management system FLccSC. To access your existing FlccSC account or Register as a new FLccSC User click here: <u>FLccSC Fundamental</u> <u>Learning Collaborative for the Cancer Surveillance Community</u>.
- See <u>Appendix I Coding Resources</u> for a list of helpful coding resources for registrars to reference when abstracting. These are intended to be used as a supplement to this Volume.

IV.1 General Guidelines for Text in the Abstract

Text documentation in all text fields should collectively record the sequence of events leading to the diagnosis and treatment of cancer.

Guidelines:

- Document in text a summary of findings and information to independently support coded data elements.
 - This provides explanation and validates interpretations and coding are correct.
 - During Audits and other QC reviews, when coded values differ from information provided by text documentation, precedence is given to text documentation.
- Include the following:
 - Pertinent patient demographic information.
 - Summarize patient presentation and diagnostic workup.
 - Record the type of cancer found.
 - Document extent of tumor spread.
 - Capture all 1st course treatment received.
 - Support the date of diagnosis.
- Abstractor verification of coded information.
 - Perform a Quality Control review of the abstract to confirm all data items are supported by text (see *Quality Control*).

IV.2 Best Practices for Text Fields

The following best practices apply to all text fields in the abstract.

Guidelines:

- Complete all text fields first before coding data items.
- Record *pertinent* cancer information only.
 - Avoid recording information not relevant to the case being reported, such as diagnostic tests/procedures for other medical conditions.
 - Document information for initial diagnostic workup and first course treatment only.
- Record dates for every procedure, diagnostic test, treatment, or significant event in applicable text fields. **Dates MUST BE DOCUMENTED in text.**
 - Acceptable formats for recording dates:

mm/dd/yyyy	02/06/2024
mm/dd/yy	02/06/24
m/d/yyyy	2/6/2024
m/d/yy	2/6/24
m/dd/yy	2/06/24

• Unacceptable formats for recording dates:

mdyyyy	262024
mmdyyyy	0262024
mmdyy	02624

- Provide supporting information to justify any estimated dates.
- Include where the procedures, diagnostic test, treatment was performed when not at the reporting facility.
 - If an exam occurred at another facility prior to admission, begin the exam findings with 'PTA.'
- Record text in a consistent, organized manner using *standard* medical abbreviations. See <u>NAACCR Abbreviations and Acronyms</u>.
- Use phrases, not complete sentences.
- Separate key phrases using either periods (.) or semi-colons (;).
- Do not leave a text field blank when information is missing from the medical record, or when there is no pertinent information. Record None, NR, or NA.
- Avoid using all capital/uppercase letters.
- Do not copy and paste entire reports into text fields.

IV.3 Text - Remarks

Certain patient and case information is recorded in *Text - Remarks*. Information that does not fit into the other text data items can also be recorded in the *Text - Remarks* area.

Text Documentation Instructions:

- The following required data must be recorded in the *Text Remarks* section when applicable:
 - Full Name of parent or guardian of a child whose case is being reported. (Information about the parent is also entered in the *Follow-Up Contact 1* area. See *Follow-Up Contacts 2 6*.
 - If the patient is participating in a protocol study, document the protocol study, clinical trial name or ID/number and study arm, as stated in the medical record. See <u>Protocol</u> <u>Participation</u>.

Examples:

- Protocol: SWOG-SO777
- Protocol: NSAPB B-39, RTOG 04313
- Protocol: RTOG-00534
- Protocol: CodeBreak 300: Colorectal Cancer/NCT05198934
- Documentation supporting the following demographic information:

- Age when the patient is 100 years or older
- o Race
 - Include text verification for the race of patient in the *Text Remarks* data item, when coded as "Other" or if there is conflicting race information. See <u>Race and</u> <u>Ethnicity</u>.
- Hispanic Origin
- o Sex
- Height, Weight
- o Smoking information to support tobacco codes
- Place of Birth if it differs from race (White female born in India)
- Record history of previous primary malignancies and/or reportable benign/uncertain behavior CNS tumors, including diagnosis date and histology, if stated.
- Supplemental information, which clarifies special circumstances that are not conveyed in the coded data items:
 - Patient was diagnosed in California but is referred to a physician or facility in another state for treatment.
 - Patient lives outside of California at the time of diagnosis and moved here for treatment.
- Record other pertinent information for which there is no designated data item.
- If text from another data item is being continued in *Text Remarks*:
 - In the data item where the text is continued *from*, enter * *Text Remarks* to indicate more information is in *Text Remarks*.
 - In *Text Remarks*, include the data item being extended and enter the overflow information. (e.g. * X-Rays/Scans: 4/2/24 CT AP: no mets).

- 1. WF born in India; Ht: 5'6", Wt: 135lbs; TOB: never; Protocol: SWOG-SO777; PMH: 2012 R Breast CA, 2024 L upper arm melanoma.
- 2. Mexican female; TOB: former cig smoker; h/o rt breast ca '10 and lt thigh melanoma '15.

IV.4 Text - Physical Examination

Enter information about the patient history, chief complaint and findings from the physical examination performed by the physician. This text field should provide enough information to understand why the patient is presenting at the reporting facility.

Text Documentation Instructions:

- For *Analytic* cases, record:
 - Date of the first physical exam reported for the cancer at your facility.
 - Chief complaint/reason for the admission.
 - Brief statement of the patient's history of the cancer (if applicable) including date of diagnosis and any relevant treatment and staging information that is not otherwise documented in other text fields.
 - Findings in the physical exam that are *pertinent* to the cancer.

- Primary site location (include laterality)
- Tumor size/extension to surrounding tissue/structures
- Lymph Node status
- Spread to distant sites
- Physician impression: anything relevant which provides physician's impression to support the diagnosis, extent of disease, stage, or planned treatment.
- For *Non-Analytic* cases, record:
 - Date of admission to your facility
 - Reason for the admission
 - Patient's history of the cancer including date of diagnosis, all relevant staging information and any 1st course treatment that occurred (record *details* of treatment in the appropriate treatment text fields).
- Do not record planned work-up.
- Do not record findings from exams that are recorded in other text fields on the abstract (X-Rays/Scans, Scopes, etc.).
- Record the date **active surveillance** was decided (when applicable). See also <u>RX Summary</u> <u>Treatment Status</u> and <u>Date of Initial RX SEER</u> (Therapy Initiated) for instructions on how to code active surveillance cases.
- Record the Managing/Treating physician's impression/statement of the patient's overall *clinical* response to neoadjuvant therapy.

- 1. Analytic Case
 - a. 10/2/24 pt presented for US guided lt breast core bx due to susp findings on screening mammo. PE: Palp mass noted in UOQ lt breast w/o palp ax LAD noted on exam.
 - b. 9/24/24 cc: rectal cancer dx at XYZ Hosp April 2024, s/p neoadjuvant chemo, XRT w/partial response, per MD; presents for surgical resection; PE: wnl.
 - c. 2/5/24 cc: elevated PSA; patient presents for prostate bx; PE: normal DRE; 3/10/24 Per Med-Onc plan is Active Surveillance.
- 2. Non-Analytic Case
 - a. (Class 30) 4/20/24 pt dx w/pancreatic cancer per imaging @ ABC medical center; presents for LN FNA/bx to confirm the diagnosis; PE: wnl.
 - b. (Class 32) 3/11/24 pt dx w/mult myeloma April 2023 at XX Hospital, on chemo but discontinued 1/2024 due to progression of spine mets; presents for 2nd course radiation therapy.

IV.5 Text - X-Ray/Scans

Document X-Ray/Scan findings in this text data item to capture relevant positive and negative findings on imaging or scans performed.

Text Documentation Instructions:

- Enter findings from X-Rays, Computerized Axial Tomography (CT or CAT scans), Magnetic Resonance Imaging (MRI), Echosonography, and other imaging used to diagnose or stage the cancer or to determine treatment response when neo-adjuvant therapy has been given.
 - Document findings from the original diagnostic workup. Do not record findings for follow-up, recurrence, or progression of disease, unless it is needed to support the data item <u>Neoadjuvant Therapy Clinical Response.</u>
- Record:
 - Date of exam(s) in chronological order.
 - For multiple exams performed on the same date, record the date once and separate exams with a period (.) or semi-colon (;)
 - Type of exam/body part examined (CT Chest; MRI Brain)
 - Where the exam was performed (if not at the reporting facility)
 - Pertinent findings, both positive and negative, that identify:
 - Primary site location (include subsite/lobe/quadrant/laterality/whether it is multi-focal)
 - Tumor size/extension to surrounding tissue/structures
 - Lymph Node status
 - Spread to distant sites
 - Capture any other clinical information needed to support site-specific data items
 - Diagnostic statement/impression of the radiologist or endoscopist, including response to neoadjuvant therapy.

- 1. PTA 2/11/24 CT AP (ABC Hosp): no tumor noted; 3/27/24 CT Chest: no E/O mets dz.
- 2. 9/20/24 MMG and LT breast US: Susp 0.5 cm mass lt breast at 2 o'clock. Nonspecific Ax LNs. 10/8/24 L Breast MRI: 1.7 cm mass, 1-2 o'clock position, No LAD.
- 3. 5/30/24 CT AP: 6cm wall thickening distal colon, peritoneal and pelvic LNs c/w susp for mets; neg for bone mets.
- 4. 09/28/24 MRI Pelvis (post neo-adj chemo): Interval decrease in high rectal tumor, now 2.8CM, previously seen LNs resolved.

IV.6 Text - Scopes

In the Scopes section of the abstract, record information for all scopes performed as part of the initial work-up of diagnosis.

Text Documentation Instructions:

- Enter the date and type of procedure performed, such as laryngoscopies, sigmoidoscopies, mediastinoscopies, colonoscopies, and other endoscopic procedures.
- Record:
 - Date of exam(s) in chronological order.
 - Type of exam/body part examined.
 - Where the exam was performed (if not at the reporting facility).
 - Pertinent findings, both positive and negative, that identify:

- Primary site location (include subsite/lobe/quadrant/laterality/whether it is multi-focal)
- Tumor size/extension to surrounding tissue/structures
- Lymph Node status
- Spread to distant sites
- Capture any other clinical information needed to support site-specific data items.
- Diagnostic statement/impression and/or stage of the endoscopist, including response to neoadjuvant therapy.
- Include mention of biopsies, washings, and other procedures performed during the examination. All results obtained from these procedures must be entered in the <u>Text</u> <u>Pathology Findings</u>.

Examples:

- 1. 1/18/24 EGD with bx: Tumor located in the distal esophagus extending into the gastric cardia for 2cm. Tumor invades through the muscularis propria and into the adventitia. Periesophageal LNs suspicious for mets. uT3N1 per endoscopist.
- 2. PTA 4/2024 Colonoscopy @ Unk facility: @35cm nearly obst mass left colon, unk if bx taken.

IV.7 Text - Laboratory Tests

Enter the findings from the laboratory tests or procedures used in establishing the diagnoses of neoplasms or metastases, such as serum protein electrophoresis for multiple myeloma or Waldenstrom's macroglobulinemia, serum alpha-fetoprotein (AFP) for liver cancer, and other tumor marker studies.

- Text must support every lab result and/or tumor marker that is used to code data items on the abstract.
- Record:
 - Lab results pertinent to primary site being reported.
 - Pertinent labs prior to surgery or treatment.
 - Pertinent labs post OP for certain primary sites.
 - Date of test(s) in chronological order.
 - Name of test
 - \circ Where the exam was performed (if not at the reporting facility).
 - Test Results document in enough detail to support the coded data item(s).
 - Normal test value/range and/or interpretation recorded in parenthesis.
 - If only the test result or interpretation is stated by the physician and there is no lab report in the chart, document results as per MD.
- Record T-and B-cell marker studies on leukemia's and lymphomas, but enter hematology reports for leukemia and myeloma under Pathology.
- Record chromosome study or cytogenetic and molecular biological data results here.

• Enter "none" if no pertinent laboratory tests were performed.

Examples:

- 1. Prostate primary:
 - a. 8/8/24 PSA: 25.5 (<4.0, elevated)
 - b. 8/8/24 PSA @ Outside facility ABC: 25.5 (elevated)
 - c. 8/8/24 PSA: 25.5 (elevated) per MD
- 2. Breast primary:
 - a. 10/2/24 ER: 100%, strong, PR: 60-70%, weak to mod, Ki-67: 20-25%, HER2 IHC: 2+, equivalent on IHC; 11/25/19 Oncotype: 13
- 3. Colon primary:
 - a. 3/5/24 CEA: 2.3 (<3.9); MSI: present, per MD Notes

IV.8 Text - Operative Findings

Enter findings from operative procedures performed during the diagnosis or treatment of the cancer.

- Record pertinent observations of the surgeon (what is seen/felt/palpated) during the surgical procedure.
- Record pertinent positive and negative results of diagnostic surgical procedures, such as biopsies, dilation and curettage (D & C), and laparotomy, as well as definitive surgery findings.
- Findings may be listed in the formal operative report (heading labeled "operative findings"), within the body of the operative report, or in the "op notes" (progress notes).
- Do not report what the surgeon did (step by step procedure) or path findings.
- Record:
 - Date of procedure(s) in chronological order.
 - Type of procedure/body part(s) biopsied/resected/removed.
 - Provide enough information to support staging/diagnostic procedure and surgery codes.
 - Type of regional lymph node procedure(s).
 - Provide enough information to support <u>Scope of Regional Lymph Node Surgery</u> codes as well as <u>Date of Regional Lymph Node Dissection</u> and <u>Date of Sentinel</u> <u>Lymph Node Biopsy</u> (when applicable).
 - \circ Where the procedure was performed (if not at the reporting facility).
 - Pertinent findings, both positive and negative, that identify:
 - Primary site location (include subsite/lobe/quadrant/laterality/whether it is multi-focal)
 - Tumor size/extension to surrounding tissue/structures
 - Lymph Node status
 - Spread to distant sites
 - Tumor tissue that was not/could not be removed

- Residual tumor status/size
- Surgical Margins/Measurements
- Record "technique only" if no findings are documented or NSF when there are no significant findings.

Examples:

- 1. 10/2/24 Lt breast core bx at 2 o'clock: technique only; 11/1/24 Lt Breast segmental mast w/SLN bx: Palp, 1 cm centrally located mass w/bx clip at 2 o'clock, completely excised w/wide clinical margin. Additional marg taken circumferentially and passed off separately. 4 SLNS identified and removed.
- 2. 06/17/2023 Exp LAP resection of Lt sigmoid colon w/coloproctostomy w/partial resection of sm bowel w/ileo-colostomy. 35 cm mass; no liver mets palp; sm bowel involvement; pelvic LN dissection.

IV.9 Text - Pathology Findings

In this text data item, enter the details needed to describe the information from the pathology or cytology reports.

Pathology reports that are consultation only are typically requested from a more experienced or specialized pathologist/lab and are generally thought to be more accurate. The CCR recommends that information from consult pathology reports be preferred over the original pathology report.

- If there is a pathology report, all the *Path Report Identifier Data Item* fields must be completed. See *Pathology Report Identifier Data Items* for further instructions.
 - If the medical record only includes "hearsay" information or the physician only refers to a report finding, but there is no report in the medical record, do not complete the *Path Report Data Items 1-5*, but include the information in the text data item.
- Include information from all pertinent pathology/autopsy reports for procedures performed at your facility and any outside slide information that may be available.
- Record reports in chronological order as follows:
 - Date specimen collected
 - Primary cancer site/tissue specimen source
 - o Laterality
 - Clearly describe what is sampled/removed (FNA, Core Bx, organ resection)
 - o Histology/Behavior/Grade
 - Tumor size (record greatest dimension only, unless other dimensions are required to support codes)
 - o Extent of disease within and beyond the primary site
 - Lymphovascular Invasion status
 - Status of Margins
 - Including any site-specific margins
 - Lymph node involvement stated as number of positive/number examined and name of lymph node chain if stated (6/12 AxLN)

- o Other tissue/organs examined and findings
- Treatment effect to neoadjuvant therapy as stated in the pathology report, including the treatment response score
- TNM Staging by the pathologist
- Pertinent biomarker results (recorded in SSDIs, used for staging, evaluate response to neoadjuvant therapy, etc.)
- Comments or reports from outside consultants (review of outside slides)
- o Addendums
- Capture any other information needed to support site-specific data items
- If additional space is needed, continue the pathology text in any other available text data item and indicate which text data item the text is extending to (e.g. * <u>*Text Remarks*</u>).

Examples:

- 1. 10/2/24 Lt breast bx at 2 o'clock: IDC w/micropapillary features, Grade II, BR 7, no LVI. 11/1/24 Lt breast: IDC w/micropapillary features, Grade II, BR 7, multifocal, 1.4 and 0.3cm, no LVI, neg margins, 0/5+ SLNS on IHC. pT1c (m) N0 (sn).
- 7/5/2023 Rt Colon bx: PD Adenoca; 8/8/2023 Rt Colon: PD adenoca, 4cm, inv muscularis propria into fibroadipose tissue, LVI-, margins neg, CRM clear by >3cm, +10/20 pericolic LNs, Liver bx+ for mets, pT3 N2b, ROS confirms.
- 11/11/24 Rectum: 1.5CM Adenocarcinoma, G2 invading through muscularis propria into pericolorectal tissue; Margins(-) CRM by 13MM, TX effect: Present: Residual cancer w/evident tumor regression, (partial response, score 2), LVI(-), Perineural INV(+), Tumor Deposits: 0, 0+/24 mesorectal LNs, ypT3 N0.

IV.10 Text - Staging

The text data item for staging is used to document staging by physicians as well as provide any additional information to support the staging data items recorded in the abstract. This can include the TNM staging assigned by the physician or physician interpretation of staging/diagnostic workup information. If the registrar is assigning stage, justification for the codes assigned can also be documented here if it is not otherwise supported in other text fields.

- Staging by physicians (other than the pathologist), including Tumor Board consensus, should be recorded in this data item when available.
 - Record the type of physician recording the stage (Managing MD, Radiation Oncologist, Registrar and MD, etc.).
 - Include TNM staging by the physician even if your facility is not collecting this information. Include both clinical and pathological staging if available. This information can be useful as it provides the physician's interpretation of the diagnostic and surgical findings which may not be apparent by the diagnostic and surgical reports alone.
 - Include any other information that is not otherwise documented in other text fields that justifies the stage assignment by the physician.
 - Staging by pathologist should be recorded in the <u>*Text*</u> <u>*Pathology*</u> <u>*Findings*</u> data item.

Example:

- 1. Per Surgeon, pre-op clinical stage was T2N0M0 Stage 1.
- 2. Per Med-Onc 5/1/16 TNM stage cT3cN1cM0 Stage 3 (Larynx).
- 3. Per MD Oncology Note, completion staging workup positive for bone mets.
- Examples of other information that can be recorded in this data item:
 - No physician staging, staging by registrar only or staging by registrar and physician.

Example:

- 1. Clinical Stage per Registrar; Pathologic stage per Managing MD and Registrar.
- 2. Clinical and Path stage per Tumor Board consensus.
- 3. Staging per registrar; no MD staging in chart.
- Staging conflicts: useful for times when QC of registry abstract is compared to the source medical record or to explain any circumstance where text documentation conflicts with TNM, EOD or Summary Stage.

Example:

- 1. Conflict between MD stage and Registrar documentation. Only partial/limited records available to Registrar MD stage recorded.
- 2. Conflict between MD staging and Registrar review of complete records-Registrar stage coded. MD stage was (document original MD stage).

IV.11 Text - Final Diagnosis

This text data item is designated for recording the final diagnosis (FDX) as determined by a **recognized medical practitioner**.

Text Documentation Instructions:

- This information is ideally found in the discharge summary or progress notes.
- Record the date of the notation and the final diagnosis. Record any staging information in <u>*Text*</u> <u>*Staging*</u>.
- If there is no final diagnosis in the medical record, please state FDX: NR; do not leave this data item blank.
- If the only information available is a pathology report, which has already been recorded, then document "No MD FDX reported" in the FDX data item.

Examples:

- 1. 5/23/24 UOQ Lt Breast, IDC, Grade II per MD
- 2. 10/15/24 Stage IIIB Rt Colon Cancer per Dr XYZ

IV.12 Text - First Course of Treatment

This section provides guidance on how to document all aspects of treatment and treatment-related information in text. In addition to the *General Guidelines for Text in the Abstract* and *Best Practices for Text Fields*, the following general instructions also apply to all the FCOT text fields:

The following information must be documented in text for all FCOT modalities:

- Date treatment started.
 - Treatment dates must be recorded in the FCOT Date fields AND treatment dates MUST ALSO BE DOCUMENTED in the Treatment Text fields. This is a National Program of Cancer Registries (NPCR) requirement.
 - If the treatment plan is **Active Surveillance**, record the date that active surveillance was decided in <u>*Text Physical Exam*</u>.
- Location of treatment (when not at reporting facility).
- Type of treatment (surgical procedure/treatment volume/modality/agent(s)/protocol/regimen) and all information needed to support the coded data items for the treatment.
- If more than one procedure/treatment performed, describe each one in chronological order.
- Discontinued treatment enter the reason treatment discontinued in the appropriate treatment text field.
- Treatment not given enter the reason no treatment given in the appropriate text field.
- Unknown if treatment given If it cannot be determined whether an intended therapy was performed, record that it was recommended but is not known if the procedure was administered.

Example: Record "Chemotherapy" recommended; unknown if given."

- Treatment planned If the MD has documented a treatment plan, but treatment has not yet been initiated, enter the "planned treatment" specifics in the respective treatment text field, including MD or facility where treatment will be delivered.
- Treatment delayed If there is a delay in planned treatment and the treatment has not been initiated, enter the "planned treatment" specifics in the respective treatment text field and the reason for the delay.

Notes:

- 1. Do not leave a text data item blank when information is missing or unknown -Record None, NR, or NA.
- 2. There is no text data item for bone marrow transplant and endocrine procedures. Record text information regarding bone marrow transplants and endocrine procedures in the immunotherapy text data item.

IV.12.1 Text - Surgery

Record information for **all** surgical procedures in the first *Text* - *Surgery* field.

- Record:
 - Date of surgical procedure.
 - Location of surgery (when not at reporting facility).
 - Name of surgical procedure, **including any lymph node procedures**. Be sure to review the operative report and verify the stated procedure(s) was performed.
 - Describe procedures in enough detail to support the code selected. For example, documenting surgery as an "excision" is not enough information if there are two or

more surgery codes for different types of excisions. Document the specific excision to support the surgery code assigned.

- Avoid recording non-pertinent information such as incidental appendectomy.
- Findings on the operative report should be documented in <u>Text Operative Findings</u>.

Examples:

- 1. 11/1/24 Lt segmental mastectomy w/SLN bx.
- 2. 4/1/24 Laparoscopic Sigmoid colectomy w/ Reg LND.
- 3. 12/15/24 R parietal lobe subtotal resection of tumor.

IV.12.2 Text - Radiation Therapy

Record information for all radiation therapy phases in the first Text - Radiation Therapy field.

Text Documentation Instructions:

- Your software vendor may allow text to be entered for *each* phase, but only one text field for all phases will be transmitted to the CCR and used during Visual Editing and other QC processes to validate coded values are correct. Documenting all the information in Phase I text eliminates the possibility of some text being "lost" when the case is transmitted to CCR.
- For each radiation phase, record in chronological order, the following information from the treatment summary:
 - Treatment start date
 - Location of treatment (when not at reporting facility)
 - If therapy is neoadjuvant per the treatment plan.
 - If treatment is started, but not completed, as prescribed.
 - o Primary Target Site/Treatment Volume, including radiation to draining lymph nodes
 - Describe the primary treatment volume in enough detail to support the code selected. For example, document "whole breast" if the entire breast is radiated.
 "Breast" is not sufficient as there are two different codes for breast: "whole" breast and "partial" breast.
 - o Treatment modality
 - E.g. Ext Beam 6MV Photons or Intracavitary Brachytherapy, HDR
 - o External Beam Planning Technique
 - E.g. IMRT, Stereotactic radiotherapy
 - Dose per fraction
 - E.g. 266 cGy
 - Number of Fractions
 - E.g. 16fx
 - Total Dose
 - E.g Total 4256 cGy

Examples:

- 1. 12/30/24-1/21/25 Whole It breast XRT, 3D-CRT, photons, 266 cGy x 16 fxs, 4256 cGy total.
- 2. 12/22/24-1/25/25 Partial lt breast XRT, 3D-CRT, electrons, 250 cGy x 3 fxs, 750 cGy total.
- 3. 10/27/24-11/02/24 Neoadj Whole pelvis 2500cGy 6MV photons 5FX, Dose/FX: 500cGy Planning Technique: 3D Conformal.

IV.12.3 Text - Systemic Therapy Fields

These instructions pertain to Text - Chemotherapy, Text - Hormone Therapy, Text - Immunotherapy.

Text Documentation Instructions:

- Use <u>SEER*Rx</u> to determine if the agent is chemotherapy, hormonal therapy, immunotherapy, or an ancillary agent (non-cancer directed).
 - If a drug regimen is given to the patient, review each agent in <u>SEER*Rx</u> separately.
 - <u>SEER*Rx</u> indicates in the Coding section if the agent should be coded on the abstract. Only include information in text for agents that should be coded.
 - Read the remarks in <u>SEER*Rx</u> carefully, as some agents should be coded only in specific circumstances (e.g. Prednisone is only coded if part of a drug regimen).
- Record the following information in the appropriate text field (e.g. Chemotherapy agent recorded in *Text-Chemotherapy*).
 - Treatment start date
 - Location of treatment (when not at reporting facility)
 - If therapy is neoadjuvant per the treatment plan
 - If treatment is started, but not completed, as prescribed
 - Agent(s)
 - Reason for no treatment if systemic therapy would be expected.
 - E.g. Patient co-morbidities
 - E.g. Patient refused recommended treatment
- Transplant/Endocrine Procedures should be recorded in *Text-Immunotherapy* since there is no corresponding text field for the Transplant/Endocrine data items. Record:
 - Date of transplant/procedure
 - Location of transplant/procedure (when not at reporting facility)
 - Type of procedure. Provide enough information to justify the <u>*Transplant/Endocrine*</u> <u>*Procedure Code*</u> data item.

Examples:

- 1. No chemo recommended:
- Text Chemotherapy: Per Dr. Smith chemo not rec based on low oncotype
- 2. Letrozole started 11/26/24:
 - Text Hormonal Therapy: 11/26/24 started Letrozole, planned x 5 yrs
- *3.* Cybor-D *regimen* started 09/01/24 for Multiple Myeloma:
 - Text Chemotherapy: 9/1/24-3/4/25 Cytoxan, Velcade
 - Text Hormonal Therapy: 9/1/24-3/4/25 Dexamethasone
 - 1. Dexamethasone can be either an ancillary agent or a hormone. Per SEER*Rx, it is coded as hormonal therapy for multiple myeloma.
- 4. Neoadjuvant chemo:
 - Text Chemotherapy: 5/5/24-9/3/24 Neoadj FOLFOX (fluorouracil, oxaliplatin) x 8 cycles.

IV.12.4 Text - Other Therapy

Record information for definitive cancer-directed therapy that cannot be assigned to any other category.

Text Documentation Instructions:

- Record:
 - Date of therapy
 - Location of therapy (when not at reporting facility)
 - Type of therapy. Provide enough information to justify the Other Therapy Code data item.

Example: Optune treatment for Glioblastoma 10/1/24 - Optune is a treatment device that fights cancerous brain tumors using electrical energy fields. Text - Other Therapy: 10/1/24 Optune treatment

IV.12.5 Text - Documenting Neoadjuvant Therapy in Text

If the patient received neoadjuvant therapy, the following information must be documented in text to support the three <u>*Neoadjuvant Therapy*</u> data items.

Text Documentation Instructions:

- **Neoadjuvant Therapy**: Document in the corresponding treatment text field(s) (e.g. <u>*Text*</u> <u>*Chemotherapy*</u>, <u>*Text*</u> <u>*Radiation Therapy*):</u>
 - If therapy is considered neoadjuvant per the treatment plan.
 - If neoadjuvant treatment is started, but not completed, as prescribed.
 - Provide enough detail to support the Neoadjuvant Therapy code assigned.
- **Neoadjuvant Therapy Clinical Response**: Document information in text to support the clinical response code that is assigned:
 - Record in <u>Text Physical Examination</u> the managing/treating physician's interpretation/statement of response to neoadjuvant therapy, when available (codes 1-5).
 - Record in <u>Text Scopes</u> and <u>Text X-Ray/Scans</u> the radiologist or endoscopist statement /impression of the response to neoadjuvant therapy when post-neoadjuvant therapy scopes/scans are done prior to resection (code 6).
 - Record in <u>*Text Pathology Findings*</u> any post-neoadjuvant biopsy and/or biomarker results used to infer a clinical response (codes 6 and 7).
- **Neoadjuvant Therapy Treatment Effect**: Document in *Text Pathology Findings* the treatment effect as stated in the path report, including the treatment response score.

Part V. Tumor Data

Part V of Volume I contain instructions and guidelines on coding tumor related data items. Items included in this section are *Primary Site*, *Laterality*, *Histology*, coding and staging systems, and pediatric staging.

Guidelines:

• For additional information on topics listed in this section, please refer to <u>Appendix H - Q-Tips</u>, for a list of topics.

- CCR Q-Tips are available in the CCR learning management system FLccSC. To access your existing FlccSC account or Register as a new FLccSC User click here: <u>FLccSC Fundamental</u> <u>Learning Collaborative for the Cancer Surveillance Community</u>.
- See <u>Appendix I Coding Resources</u> for a list of helpful coding resources for registrars to reference when abstracting. These are intended to be used as a supplement to this Volume.

V.1 Primary Site

Primary site is the anatomic position of where the primary tumor developed. It is essential to identify the original (primary) site of a tumor rather than a metastatic (secondary) site.

Sources:

- The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Primary Site* data item.
- The current <u>Solid Tumor Rules</u> is to be used for determining single vs. multiple primary sites.

V.2 Laterality

Laterality describes the side of a paired organ or the side of the body on which the reportable tumor originated, which is not captured in topographic codes. The *Laterality* data item applies only to the primary site. Its main purpose is to identify the origin of the tumor.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Laterality* data item.

V.3 Diagnostic Confirmation

Records the best method used to confirm the presence of the cancer being reported. The best method could occur at any time throughout the entire course of the disease. It is not limited to the confirmation at the time of initial diagnosis. The most conclusive method should be coded in the *Diagnostic Confirmation* data item.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Diagnostic Confirmation* data item.

V.4 ICD-O Morphology - Histology and Behavior

The morphology code indicates the type of cell that has become neoplastic (histology) and its biologic activity (behavior). The CCR has adopted the *ICD-O-3.2* (*International Classification of Diseases for Oncology, Third Edition, Second Revision*) as its official morphology code system for all cases diagnosed January 1, 2001 forward.

There are no updates for 2025 ICD-O-3.2. Please continue to use the <u>2024 ICD-O-3.2 - Coding</u> <u>Tables</u>, and see the <u>2025 ICD-O-3.2 Implementation Guidelines</u>. Use of these guidelines are required for determining reportability and accurate coding.

Sources:

• For <u>solid tumors</u> diagnosed January 1, 2018 and forward, refer to the current <u>Solid Tumor</u> <u>Rules</u>.

- For <u>hematopoietic and lymphoid cases</u> diagnosed January 1, 2018 and forward, please refer to the <u>Hematopoietic and Lymphoid Neoplasm Database and Hematopoietic & Lymphoid</u> <u>Neoplasm Coding Manual</u>.
- For Site Morphology Validation Lists, see <u>Cancer Pathology Coding Histology and</u> <u>Registration Terminology (Cancer PathCHART)</u>. This can also be accessed by going to the following URL: <u>https://seer.cancer.gov/cancerpathchart/</u>.

Definitions:

- **Histology** identifies the specific cell type of the tumor. Specific cell lines come from different tissues and are extremely important information for the diagnosis and treatment of the disease. *Examples:*
 - Adenocarcinoma: is typically a cancer that begins in glandular (secretory) cells. Glandular cells are found in tissue that lines certain internal organs and makes and releases substances in the body, such as mucus, digestive juices, or other fluids. Most cancers of the breast, pancreas, lung, prostate, and colon are adenocarcinomas.
 - **Squamous cell carcinoma:** Cancer that begins in squamous cells. Squamous cells are thin, flat cells that look like fish scales, and are found in the tissue that forms the surface of the skin, the lining of the hollow organs of the body, and the lining of the respiratory and digestive tracts. Most cancers of the anus, cervix, head and neck, and vagina are squamous cell carcinomas (also called epidermoid carcinoma).
 - **Melanoma:** A form of cancer that begins in melanocytes (cells that make the pigment melanin). It may begin in a mole (skin melanoma), but can also begin in other pigmented tissues, such as in the eye or in the intestines.
- **Behavior** indicates whether a tumor is malignant or benign, or uncertain whether benign or malignant.

V.4.1 Histologic Type ICD-O-3

Histology is the study of the minute structure of cells, tissues, and organs in relation to their functions. It is primarily through histological analysis that neoplasms are identified. Determination of the correct histology code can be one of the most difficult aspects of abstracting. Training and experience are essential for development of the ability to assign the correct code. The rules are taken from the <u>SEER</u> <u>Program Coding and Staging Manual</u>.

Sources:

- For <u>solid tumors</u> diagnosed January 1, 2018 and forward, refer to the current <u>Solid Tumor</u> <u>Rules</u>.
- For <u>hematopoietic and lymphoid cases</u> diagnosed January 1, 2018 and forward, please refer to the <u>Hematopoietic and Lymphoid Neoplasm Database and Hematopoietic & Lymphoid</u> <u>Neoplasm Coding Manual</u>.

V.4.2 Unspecified Malignancies

Unspecified malignancies are those malignancies in which a specific histologic type has not been identified.

• For <u>solid tumors</u> diagnosed January 1, 2018 and forward, refer to the current <u>Solid Tumor</u> <u>Rules</u>.

V.4.3 Behavior

The Behavior Code describes the malignant potential of the tumor. Codes range from /0-benign to /3-malignant (invasive). The fifth digit of the morphology code is the Behavior Code.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Behavior* data item.

V.5 Grade and Differentiation

Grade is a measurement of how closely the tumor cells resemble the parent tissue (organ of origin).

Grade is coded in separate, specific data items as follows:

- Grade Clinical (2018+)
- *Grade Pathological* (2018+)
- *Grade Post Therapy Clin* (*yc*) (2021+)
- *Grade Post Therapy Path (yp) (2018+)*

Source: The <u>*Grade Coding Instructions and Tables*</u> are to be used for coding instructions and guidelines for the *Grade* data items.

Grade questions should be directed to CAnswer Forum at: http://cancerbulletin.facs.org/forums/.

V.6 Tumor Size

Tumor Size Clinical and Tumor Size Pathologic were collected by the CCR between 2016 and 2023 to capture information on tumor size of the solid, primary tumor at various points in the diagnosis and treatment of the reportable neoplasm. *Tumor Size Summary* was also collected starting in 2016 and will continue to be collected going forward.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Tumor Size Summary* data item.

V.7 Mets at Diagnosis Bone, Brain, Liver, Lung, Distant Lymph Nodes, and Other

The following data items record the specific site(s) of metastatic disease present at diagnosis. Each data item identifies whether bone, brain, distant lymph nodes, liver, lung or other discontinuous or distant metastatic site(s) are involved.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Mets at Diagnosis* data items.

V.8 Lymphovascular Invasion

The *Lymphovascular Invasion* data item identifies the presence or absence of tumor cells within blood vessels, lymphatic channels (not lymph nodes) or surrounding tissue within the primary tumor as noted microscopically by the pathologist. Lymphovascular invasion (LVI) includes lymphatic, vascular, and lymphovascular invasion as an indicator of prognosis.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Lymphovascular Invasion* data item.

CCR Specific Coding Instructions:

Standard Setter Differences:

- The CCR requires Lymphovascular Invasion (LVI) to be coded for penis and testis for cases diagnosed 1/1/2010 and forward, and for all sites when available.
- SEER requires Lymphovascular Invasion (LVI) to be coded for penis and testis only.

V.9 Stage at Diagnosis

Stage at Diagnosis is the established extent of disease determined after the diagnostic/staging workup for a new cancer. Staging requirements have evolved over the years. This section provides a view of the changes over the last few years at a glance.

Guidelines:

- Methods commonly used to determine stage are the American Joint Committee on Cancer (AJCC) TNM staging system, SEER Summary Stage 2018, SEER Extent of Disease, and Site-Specific Data Items:
 - AJCC TNM: Used in the clinical setting by physicians to define spread of disease to make appropriate treatment decisions, determine prognosis, and measure end results. Refer to the most current <u>AJCC Cancer Staging Manual</u> for coding instructions.
 - The <u>Version 9 Cancer Staging System</u> is an update to the AJCC 8th Edition replacing selected disease site(s) on an annual basis. All 8th Edition disease sites remain in effect unless replaced by a new Version 9 protocol.
 - The <u>Standards for Oncology Registry Entry (STORE)Manual</u> is to be used for coding instructions and guidelines for all AJCC TNM Staging data items, including guidelines for Ambiguous Terms Describing Tumor Spread for this staging system.
 - AJCC Cancer Staging questions should be directed to the CAnswer Forum at: <u>http://cancerbulletin.facs.org/forums</u>.
 - **SEER Summary Stage 2018:** Used by Epidemiologists and researchers where cases are grouped into standardized and simplified broad categories to ensure consistent definitions over time.
 - Refer to the most current <u>SEER Summary Stage 2018 Manual</u> for coding instructions including guidelines for Ambiguous Terms Describing Tumor Spread for this staging system.
 - Summary Stage 2018 questions should be directed to ask a SEER Registrar at: <u>https://seer.cancer.gov/registrars/contact.html</u>.
 - SEER Extent of Disease: Reflects a combination of clinical and pathologic information. Permits staging of all cancer types. Allows calculation of a combined "best" stage.
 - Refer to the most current <u>Extent of Disease 2018 General Instructions</u> and <u>SEER*RSA</u> for coding instructions including guidelines for Ambiguous Terms Describing Tumor Spread for this staging system.
 - Extent of Disease questions should be directed to ask a SEER Registrar at: <u>https://seer.cancer.gov/registrars/contact.html</u>

- Site-Specific Data Items: Consist of additional prognostic factors or schema discriminators, which are cancer site-specific. Some are used in combination with staging systems variables to determine or derive a stage.
 - Refer to the most current <u>Site-Specific Data Items Manual</u> and <u>SEER*RSA -</u> <u>Cancer Schema List</u> for coding instructions.
 - Required from ALL facilities by CCR unless otherwise specified in <u>Appendix F</u> <u>- Site-Specific Data Items (SSDIs).</u>
 - Site-Specific Data Item SSDI questions should be directed to CAnswer Forum at: <u>http://cancerbulletin.facs.org/forums</u>
- Pediatric Data Collection System (PDCS): This data collection system has been developed to collect Pediatric staging and site-specific data item (SSDI) information. The staging elements collected are based on the *Toronto Childhood Cancer Staging Guidelines, Version 2,* along with additional data items for surveillance purposes. The PDCS should not be confused with <u>Pediatric Stage</u> that has been collected by the CCR since 1996.
 - Refer to the <u>Pediatric Staging Manual</u> and <u>Pediatric Staging on SEER*RSA</u> for coding instructions.
 - The CCR requires the PDCS data items from **participating registries only**. This applies to cases diagnosed January 1, 2024 forward or January 1, 2025 depending on data item.
 - Pediatric Data Collection System (PDCS) questions should be directed to Ask a SEER Registrar at: <u>https://seer.cancer.gov/registrars/contact.html</u>
- For staging requirements prior to 2018, please see <u>Archived Volume I</u> Use case year of diagnosis to determine which Volume I to choose.
- Staging of in-situ cases differ by Standard Setter. Please see links above to review differences.

Staging System Data/Collection	2018-2025
AJCC Version 9 Cancer Staging System; Clinical & Path Stage Directly Coded	 Required from CoC facilities only: Cervix - diagnosed 2021+ Anus, Appendix, Brain & Spinal Cord/Medulloblastoma - diagnosed 2023+ NET Appendix, NET Colon and Rectum, NET Duodenum and Ampulla of Vatter, NET Jejunum and Ileum, NET Pancreas, NET Stomach, Vulva - diagnosed 2024+ Thymus, Lung, Diffuse Pleural Mesothelioma, Nasopharynx - diagnosed 2025+
AJCC TNM 8 th Edition Clinical & Path Stage Directly Coded	Required from CoC facilities only, for cases diagnosed 2018+
Pediatric Data Collection System (PDCS)	Required, if available, Site-Specific, from all facilities, for cases diagnosed 2025+
SEER 2018 Extent of Disease (EOD) Directly Coded	Required from ALL facilities for cases diagnosed 2018+
Summary Stage 2018 Directly Coded	Required from ALL facilities for cases diagnosed 2018+

Staging Requirements 2018-2025

V.10 SEER Site-Specific Factor 1

SEER Site-Specific Factor 1 is reserved for capturing information on human papilloma virus (HPV) status. There is evidence that HPV plays a role in pathogenesis of some cancers. HPV testing may be performed for prognostic purposes; testing may be performed on metastatic sites to aid in determination of the primary site. This data item is required by the CCR for cases diagnosed January 1, 2018 and forward.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the SEER Site-Specific Factor 1 data item.

V.11 Pediatric Stage

Pediatric staging refers to cancer staging that is specific to pediatric patients, which may differ in some instances from staging of adult cancers. Pediatric Stage includes patients who are younger than twenty (20) years of age. The CCR requires this data for pediatric cases only, diagnosed January 1, 1996 and forward.

Common pediatric cancers are often managed using clinical protocols and are treated in pediatric centers. Many pediatric cancers are staged using specialized systems which are histology and tumor site driven per clinical trials. Some pediatric cancers such as Lymphoma are staged using the same AJCC TNM staging system used for adults.

The Pediatric Stage data items should not be confused with the new Pediatric Data Collection System (PDCS) introduced by SEER for 2025. Please see <u>Stage at Diagnosis</u> for additional information on PDCS.

Coding Instructions:

- If AJCC staging is used to stage a pediatric case, refer to the most current <u>AJCC Cancer</u> <u>Staging Manual</u> for coding instructions.
- When Summary Stage is used, for cases or tumors diagnosed January 1, 2018 and forward, refer to the *SEER Summary Stage 2018 Manual* for coding instructions.
- In the event another staging system is used, please specify the staging method used.
- Document the stage and method used in the <u>*Text*</u> <u>*Staging*</u> data item.

V.11.1 Pediatric Stage Group

Pediatric Stage Group refers to the stage group assigned for the pediatric cancer. *Pediatric Stage Group* is to be used for entering the stage for pediatric patients only. The CCR requires this data for pediatric cases only, diagnosed January 1, 1996 and forward.

Coding Instructions:

- Pediatric stage includes patients who are younger than twenty (20) years of age and diagnosed January 1, 1996 or later.
- Record the stage assigned by the managing provider.

- This scheme is to be used for entering the stage for pediatric patients only.
- Code 88 (not applicable) for patients twenty years of age and older.
- Code 99 for pediatric leukemia cases.

Code	Description	
1	Stage I	
1A	Stage IA (rhabdomyosarcomas & related sarcomas)	
1B	Stage IB (rhabdomyosarcomas & related sarcomas)	
2	Stage II	
2A	Stage IIA (rhabdomyosarcomas & related sarcomas)	
2B	Stage IIB (rhabdomyosarcomas & related sarcomas)	
2C	Stage IIC (rhabdomyosarcomas & related sarcomas)	
3	Stage III	
3A	Stage IIIA (liver, rhabdo. & related sarcomas, Wilms')	
3B	Stage IIIB (liver, rhabdo. & related sarcomas, Wilms')	
3C	Stage IIIC (Wilms' tumor)	
3D	Stage IIID (Wilms' tumor)	
3E	Stage IIIE (Wilms' tumor)	
4	Stage IV	
4A	Stage IVA (bone)	
4B	Stage IVB (bone)	
4S	Stage IVS (neuroblastoma)	
5	Stage V (Wilms' tumor/retinoblastoma)	
А	Stage A (neuroblastoma)	
В	Stage B (neuroblastoma)	
С	Stage C (neuroblastoma)	
D	Stage D (neuroblastoma)	
DS	Stage DS (neuroblastoma)	
88	Not Applicable (not a pediatric case)	
99	Unstaged, Unknown	

V.11.2 Pediatric Protocols

Pediatric Protocols refer to the specialized systems used to stage pediatric cancers. These systems are based on histologic type and/or primary site. The CCR requires this data for pediatric cases only, diagnosed January 1, 1996 and forward.

Coding Instructions:

• Use for pediatric patients **only**.

• Record the staging system used by the managing provider.

Code	Description
00	None
01	American Joint Committee on Cancer (AJCC)
02	Ann Arbor
03	Children's Cancer Group (CCG)
04	Evans
05	General Summary
06	Intergroup Ewing's
07	Intergroup Hepatoblastoma
08	Intergroup Rhabdomyosarcoma
09	International System
10	Murphy
11	National Cancer Institute (Pediatric Oncology)
12	National Wilms Tumor Study
13	Pediatric Oncology Group (POG)
14	Reese Ellsworth
15	SEER Extent of Disease
16	Children's Oncology Group (COG)
88	Not Applicable
97	Other
99	Unknown

V.11.3 Staged By - Pediatric Stage

Staged By - Pediatric Stage data item identifies the person who assigned the cancer stage. The CCR requires this data for pediatric cases only, diagnosed January 1, 1996 and forward.

Coding Instructions:

- This data item is to be used for pediatric cases only diagnosed January 1, 1996 and forward. It identifies the person who staged the case.
- The ACS states that the managing provider is responsible for staging analytical cases.
 - The CCR concurs and feels that this applies to non-analytic cases, also.
- If the staging has not been done by the provider, the registrar does not have to stage the case.
 - \circ Enter 0 for not staged.
- Code 0 for patients older than twenty (20).

	Code	Description
ſ	0	Not staged

1	Managing physician
2	Pathologist
3	Other physician
4	Any combination of 1, 2, or 3
5	Registrar
6	Any combination of 5 with 1, 2, or 3
7	Other
8	Staged, individual not specified
9	Unknown if staged

Part VI. First Course of Treatment

Part VI of Volume I consists of first course of treatment. Instructions included in this section range from surgery, radiation, chemotherapy, hormone therapy, immunotherapy, transplant/endocrine therapy and other therapy, to the summary of treatment status and protocol participation.

Guidelines:

- For additional information on topics listed in this section, please refer to <u>Appendix H Q-Tips</u>, for a list of topics.
- CCR Q-Tips are available in the CCR learning management system FLccSC. To access your existing FlccSC account or Register as a new FLccSC User click here: <u>FLccSC Fundamental</u> <u>Learning Collaborative for the Cancer Surveillance Community</u>.
- See <u>Appendix I Coding Resources</u> for a list of helpful coding resources for registrars to reference when abstracting. These are intended to be used as a supplement to this Volume.

VI.1 Definitions and Guidelines - First Course of Treatment

First course treatment is all treatments administered to the patient after the original diagnosis of cancer in an attempt to destroy or modify the cancer tissue.

IMPORTANT Note: This section applies to all neoplasms (including benign and borderline intracranial and CNS tumors) **except** hematopoietic and lymphoid neoplasms. For hematopoietic and lymphoid cases diagnosed January 1, 2018 and forward, please refer to the <u>Hematopoietic and</u> <u>Lymphoid Neoplasm Coding Manual</u> for information on coding first course treatment for these cases.

Record all cancer directed therapeutic procedures (surgery, radiation, systemic, or other therapy) administered at any facility, whether in a primary or metastatic site, whatever the mode of treatment, and regardless of the sequence and degree of completion of any component part.

CCR Expectations:

• The CCR expects every reporting facility that has a tumor registry to obtain information about the entire first course therapy from the medical record and, if necessary, the physicians themselves, regardless of where the treatment was administered.

- Reporting facilities preparing initial case reports for the sole purpose of meeting state mandatory reporting requirements may elect to record only the treatment documented in their medical records.
- Abstractors are provided with two data items to record first course of treatment information.
 - The first treatment data item for each modality (except surgery) is known as "*Treatment Summary*." This data item should include any first course treatment administered for that modality, regardless of where it was administered, including treatment administered at the reporting facility.
 - The second treatment data item for each modality (except surgery) is known as "*Treatment at this reporting facility*." This data item should only include first course treatment administered at the reporting facility, respective to each modality.
 - Treatment given by a physician on the medical staff of a facility should not be recorded as treatment given at that reporting facility, effective with cases diagnosed January 1, 1998 and forward.
 - If <u>Class of Case</u> is coded to 00, 30, or 32, record the associated "none" code (e.g. 00, 0) for the "At this Facility" data item.
- Referral to an oncologist is considered a recommendation. Registry personnel should follow-up on these cases to determine whether chemotherapy was administered or not, and code accordingly. This applies to cases diagnosed January 1, 2010 and forward. Prior to January 1, 2010, referral did not equal a recommendation.
- The CCR requires **all** treatment information to be recorded in text fields. See <u>*Text First Course of Treatment*</u> for specific requirements.

VI.1.1 Neoadjuvant Treatment - First Course of Treatment

Systemic treatment (chemotherapy, endocrine/hormone therapy, targeted therapy, immunotherapy, or biological therapy) and/or radiation treatment given prior to surgical resection to improve outcomes. This treatment is also sometimes referred to as pre-surgical or preoperative treatment. *Neoadjuvant Therapy, Neoadjuvant Therapy Clinical Response, and Neoadjuvant Therapy - Treatment Effect* data items are required by the CCR to be collected for cases diagnosed January 1, 2021 and forward:

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the neoadjuvant data items.

VI.1.2 Treatment Facility Number

The CCR assigned reporting facility code for the reporting facility or agency that provided first course treatment.

Coding Instructions:

- Refer to the most current <u>California Reporting Facility Codes</u> lists, located on the CCR website <u>https://www.ccrcal.org/</u>, Registrar Resources, Reporting Cancer in California, Volumes I-V.
 - Lists are presented in both alphabetical and code order.
- The data items are to be left blank if no cancer-directed surgery was performed.
- These data items are used in conjunction with each surgical procedure performed.

VI.2 Surgery Introduction - First Course of Treatment

In abstracting surgical treatment, the total or partial removal (except an incisional biopsy) of tumor tissue must be recorded in the appropriate text data item, whether from a primary or metastatic site. See *Text Documentation* for additional information.

Guidelines:

- Surgical procedures are coded in four-character alphanumeric codes, beginning with cases diagnosed January 1, 2023. For cases diagnosed prior to 2023, see <u>Archived Volume I</u>. Use case year of diagnosis to determine which Volume I to choose.
- The CCR allows up to 3 surgical procedures to be collected.
 - Enter the procedures in chronological order.
 - If there are more than 3 surgical procedures, always record the first procedure and also the most definitive surgery of primary site.
 - The following data items are collected for each procedure:
 - Date of Surgical Procedure. See *Entering Dates*.
 - Surgery of the Primary Site 2023
 - Scope of Regional Lymph Node Surgery
 - o Surgery of Other Regional/Distant Sites
- The CCR collects pathology report identifiers that correspond to the diagnostic/staging and surgical procedures collected on the abstract. See <u>Pathology Report Identifier Data Items</u> for more information.
- For a supplemental resource for coding melanoma cases, see <u>STORE, Appendix M Case</u> <u>Studies for Coding Melanoma in STORE</u>, for case scenarios.

Standard Setter Differences:

- The CCR does not require that palliative treatment/procedures be recorded but the CoC does require this data item. The STORE Manual is linked above for instructions regarding the palliative procedure data item. This applies to cases diagnosed January 1, 2003 forward.
- The CCR follows SEER guidelines for assigning surgery codes. COC Facilities: Please make note in your user defined data items when standards between CoC and CCR differ.

VI.2.1 Surgery Data Items - Refer to STORE

Source: The <u>Standards for Oncology Registry Entry (STORE)</u> is to be used for coding instructions and guidelines for the surgical data items listed below. The manual can also be accessed by going to the following URL: <u>https://www.facs.org/quality-programs/cancer-programs/national-cancer-database/ncdb-data-submission/</u>.

- **Diagnostic or Staging Procedures** Record surgical procedures performed solely for establishing a diagnosis and/or determining stage of disease. If more than one surgical diagnostic or staging procedure was done, record the first performed.
- Macroscopic Evaluation of the Mesorectum This data item records whether a total mesorectal excision (TME) was performed and the macroscopic evaluation of the completeness of the excision. This applies to rectal cases only. This data item is required by CoC-accredited facilities for all cases diagnosed January 1, 2022 and forward.

• **Breast Reconstruction** - Describes the reconstruction procedure immediately following resection of the breast. This item was previously collected within the breast surgery codes. Collection of this new data item supports the Synoptic Operative Report and allows for more descriptive reconstruction codes. This data item is required by the CCR for cases diagnosed January 1, 2024 and forward.

Note: The codes for this data item are **NOT** the same as those for the *Surgery of Primary Site* 2023.

For a supplemental resource for coding melanoma cases, see <u>STORE, Appendix M - Case Studies for</u> <u>Coding Melanoma in STORE</u>, for case scenarios.

VI.2.2 Surgery Data Items - Refer to SEER

Sources: The <u>SEER Program Coding and Staging Manual</u> and the <u>SPM-Appendix C - Site-Specific</u> <u>Coding Modules</u> are to be used for coding instructions and guidelines for following surgical data items. For a supplemental resource for <u>melanoma cases</u>, see <u>STORE, Appendix M - Case Studies for</u> <u>Coding Melanoma in STORE</u>, for case scenarios.

- **Surgery of Primary Site 2023** This data item describes a surgical procedure that removes and/or destroys tissue of the primary site that is performed as part of the initial diagnostic and staging work-up or first course of therapy. This data item is required by the CCR for cases diagnosed January 1, 2023 and forward.
- Surgical Margins of the Primary Site This data item describes the final status of the surgical margins after resection of the primary tumor. It is used in staging, for quality assurance measures, and may be a prognostic factor in recurrence. Surgical margins are required by the CCR to be coded for all primary sites. This applies to cases diagnosed January 1, 2016 and forward.
- Scope of Regional Lymph Node Surgery This data item is used to record the procedures performed to remove, biopsy, or aspirate regional lymph nodes during the initial work-up or first course of therapy.
 - See <u>CCR Scope of Regional Lymph Node Surgery Tables</u>
 - See <u>Sentinel Lymph Node Biopsy</u> for CCR Specific Guidelines
- Surgery of Other Regional Sites, Distant Sites, or Distant Lymph Nodes This data item refers to the surgical removal of sites other than the primary site. There are three one-character data items that capture the removal of tissue other than the primary tumor or organ of origin. This would not include an en bloc resection.
- **Date of Regional Lymph Node Dissection** Records the date non-sentinel regional lymph node dissection (RLND) was performed. This data item can be used to more accurately assess the date of regional node dissection separate from the date of sentinel lymph node biopsy if performed. This data item is required by CoC-accredited facilities for all cases diagnosed January 1, 2018 and forward.
- **Regional Lymph Nodes Positive** This data item records the exact number of regional lymph nodes examined by the pathologist and found to contain metastases.

Note: Effective with cases diagnosed January 1, 2016 and forward, the AJCC definition takes precedence if the definition of regional nodes differs between the current <u>AJCC Cancer</u> <u>Staging Manual</u> and the <u>SEER Program Coding and Staging Manual</u>.

• **Regional Lymph Nodes Examined** - This data item records the total number of regional lymph nodes that were removed and examined by the pathologist.

Note: Effective with cases diagnosed January 1, 2016 and forward, the AJCC definition takes precedence if the definition of regional nodes differs between the <u>AJCC Cancer Staging</u> <u>Manual</u> and the <u>SEER Program Coding and Staging Manual</u>.

- Date of Sentinel Lymph Node Biopsy Enter the date of the sentinel lymph node(s) biopsy procedure. This data item is required by the CCR for breast and cutaneous melanoma cases only diagnosed January 1, 2018 and forward.
 - o See <u>Sentinel Lymph Node Biopsy</u> for CCR Specific Guidelines
- Sentinel Lymph Nodes Positive This data item records the exact number of sentinel lymph nodes found to contain metastases. This data item is required by the CCR for breast and cutaneous melanoma cases only diagnosed January 1, 2018 and forward.
- Sentinel Lymph Nodes Examined This data item records the total number of lymph nodes sampled during the sentinel node biopsy and examined by the pathologist. This data item is required by the CCR for breast and cutaneous melanoma cases only diagnosed January 1, 2018 and forward.
- **Special Rules for Counting Lymph Nodes** Special rules for counting regional lymph nodes, gives guidance as to what to do when a core needle biopsy or aspiration is followed by a dissection.
- **Surgery of Synchronous Primaries** Synchronous Primaries are multiple histologically distinct tumors diagnosed simultaneously.
- **Systemic Therapy with Surgery Sequence** This data item documents the sequence in which systemic therapy and surgical procedures were performed as part of the first course of treatment.
- **Reason for No Surgery of the Primary Site** Record the reason the patient did not have surgery to the primary site. Reason for No Surgery only applies to the *Surgery of the Primary Site 2023* data item, **not** *Scope of Regional Lymph Node Surgery* or *Surgery Other Regional/Distant Sites*.

VI.2.3 Sentinel Lymph Node Biopsy

It is a known fact that sentinel lymph node biopsies have been under-reported. Additionally, the timing and results of sentinel lymph node biopsy procedures are used in quality of care measures.

CCR Specific Guidelines:

- Sentinel lymph nodes (SLNs) are the first lymph nodes (LNs) to which cancer cells are most likely to spread from the primary tumor.
- Sentinel lymph node biopsy (SLNBx) is a procedure in which a sentinel LN is identified, removed, and examined.
 - By injection of a radioactive tracer substance and/or blue dye near the tumor, sentinel lymph nodes can be identified when they "map" or are described as "hot" from radiotracer uptake, or described "blue" resulting from dye uptake.
 - Usually 1-3 sentinel LNs will be identified, however, non-sentinel LNs may be in very close proximity to SLNs and may need to be excised in the process of dissecting the SLNs.

- All LNs removed in this bundle during the sentinel lymph node procedure are counted and coded in the number of sentinel LNs examined even if the node(s) were described as "non-sentinel," "failed to map," and/or did not contain dye or radio tracer.
- All LNs removed in this bundle during the sentinel lymph node procedure and identified as positive by the pathologist, are counted and coded as positive even if the node(s) were described as "non-sentinel," "failed to map," and/or did not contain dye or radio tracer.
- A SLN biopsy is performed when lymph nodes (LNs) are clinically negative and may be followed by a full regional lymph node (LN) dissection when:
 - Nodes "fail to map" or
 - SLNs are found to be positive
- Failure to map occurs when no nodes will uptake either the radiotracer substance or the blue dye.
- If a relatively large number of LNs (>5) are removed, more investigation needs to be done.
- READ the operative report to clarify that the procedure was limited to a SLNBx and did not include a full regional LN dissection. This **cannot** be determined from the path report.
- Generally performed for breast and cutaneous melanoma cancers.

VI.2.4 CCR Scope of Regional Lymph Node Surgery Tables

The CCR is including code tables for the *Scope of Regional Lymph Node Surgery* data item to <u>augment</u> the <u>SEER Program Coding and Staging Manual</u> instructions. The CCR tables provide more guidance/clarifications than is provided in the SEER Manual, but the requirements are the same. **Do not use these tables alone**. See coding instructions for *Scope of Regional Lymph Node Surgery* in the *SEER Program Coding and Staging Manual* linked above.

Codes (all sites excluding Breast):

For breast sites, see Codes (Breast Only)

Code	Label	All Sites (except Breast, see table below)
0	NO REGIONAL LYMPH NODE SURGERY	No regional lymph node surgery
1	BIOPSY OR ASPIRATION OF REGIONAL LYMPH NODE(S)	Review the operative report to confirm whether an excisional biopsy or aspiration of regional lymph nodes was actually performed. If additional procedures were performed on the lymph nodes, use the appropriate code 2-7
2	SENTINEL LYMPH NODE BIOPSY	The operative report states that a SLNBx was performed Code 2 SLNBx when the operative report describes a procedure using injection of a dye, radio label, or combination to identify a lymph node (possibly more than one) for removal/examination
		When a SLNBx is performed, additional non-sentinel nodes can be taken during the same operative procedure. These additional non-sentinel nodes may be discovered by the pathologist or selectively removed (or harvested) as part of the

		SLNBx procedure by the surgeon. Code this as a SLNBx (code 2). If review of the operative report confirms that a regional lymph node dissection followed the SLNBx, code these cases as 6
3	NUMBER OF REGIONAL LYMPH NODES REMOVED UNKNOWN OR NOT STATED; REGIONAL LYMPH NODES REMOVED, NOS OR NOT STATED; REGIONAL LYMPH NODES REMOVED, NOS	The operative report states that a regional lymph node dissection was performed (a SLNBx was not done during this procedure or in a prior procedure) Code 3 (Number of regional lymph nodes removed unknown, not stated; regional lymph nodes removed, NOS). Check the operative report to ensure this procedure is not a SLNBx only (code 2), or a SLNBx with a regional lymph node dissection (code 6 or 7) Code 4 (1-3 regional lymph nodes removed) should be used infrequently. Review the operative report to ensure the procedure was not a SLNBx only Code 5 (4 or more regional lymph nodes removed). If a relatively small number of nodes were examined pathologically, review the operative report to confirm the procedure was not a SLNBx only (code 2). If a relatively large number of nodes were examined pathologically, review the operative report to confirm that there was not a SLNBx in addition to a more extensive regional lymph node dissection during the same, or separate, procedure (code 6 or 7) Infrequently, a SLNBx is attempted, and the patient fails to map (i.e. no sentinel lymph nodes are identified by the dye and/or radio label injection). When mapping fails, surgeons usually perform a more extensive dissection of regional lymph nodes. Code these cases as 2 if no further dissection of regional lymph nodes was undertaken, or 6 when regional lymph nodes were dissected during the same operative event
4	1-3 REGIONAL LYMPH NODES REMOVED	The operative report states that a regional lymph node dissection was performed (a SLNBx was not done during this procedure or in a prior procedure) Code 3 (Number of regional lymph nodes removed unknown, not stated; regional lymph nodes removed, NOS). Check the operative report to ensure this procedure is not a SLNBx only (code 2), or a SLNBx with a regional lymph node dissection (code 6 or 7) Code 4 (1-3 regional lymph nodes removed) should be used infrequently. Review the operative report to ensure the procedure was not a SLNBx only Code 5 (4 or more regional lymph nodes removed). If a relatively small number of nodes were examined pathologically, review the operative report to confirm the procedure was not a SLNBx only (code 2). If a relatively large number of nodes were examined pathologically, review the operative report to confirm that there was not a SLNBx in addition to a more extensive regional lymph node dissection during the same, or separate, procedure (code 6 or 7) Infrequently, a SLNBx is attempted, and the patient fails to map (i.e. no sentinel lymph nodes are identified by the dye and/or radio label injection). When mapping fails, surgeons usually perform a more extensive dissection of regional lymph

		nodes. Code these cases as 2 if no further dissection of regional lymph nodes was undertaken, or 6 when regional lymph nodes were dissected during the same operative event
5	4 OR MORE REGIONAL LYMPH NODES REMOVED	The operative report states that a regional lymph node dissection was performed (a SLNBx was not done during this procedure or in a prior procedure) Code 3 (Number of regional lymph nodes removed unknown, not stated; regional lymph nodes removed, NOS). Check the operative report to ensure this procedure is not a SLNBx only (code 2), or a SLNBx with a regional lymph node dissection (code 6 or 7) Code 4 (1-3 regional lymph nodes removed) should be used
		infrequently. Review the operative report to ensure the procedure was not a SLNBx only Code 5 (4 or more regional lymph nodes removed). If a relatively small number of nodes were examined pathologically, review the operative report to confirm the procedure was not a SLNBx only (code 2). If a relatively large number of nodes were examined pathologically, review the operative report to confirm that there was not a SLNBx in addition to a more extensive regional lymph node dissection during the same, or separate, procedure (code 6 or 7)
		Infrequently, a SLNBx is attempted, and the patient fails to map (i.e. no sentinel lymph nodes are identified by the dye and/or radio label injection). When mapping fails, surgeons usually perform a more extensive dissection of regional lymph nodes. Code these cases as 2 if no further dissection of regional lymph nodes was undertaken, or 6 when regional lymph nodes were dissected during the same operative event
6	SENTINEL NODE BIOPSY AND CODE 3, 4, OR 5 AT THE SAME TIME, OR TIMING NOT STATED	 SLNBx and regional lymph node dissection (code 3, 4, or 5) during the same surgical event, or timing not known Generally, SLNBx followed by a regional lymph node completion will yield a relatively large number of nodes. However, it is possible for these procedures to harvest only a few nodes If relatively few nodes are pathologically examined, review the operative report to confirm whether the procedure was limited to a SLNBx only Infrequently, a SLNBx is attempted, and the patient fails to map (i.e. no sentinel lymph nodes are identified by the dye and/or radio label injection.) When mapping fails, the surgeon usually performs a more extensive dissection of regional lymph nodes. Code these cases as 6
7	SENTINEL NODE BIOPSY AND CODE 3, 4, OR 5 AT DIFFERENT TIMES	SLNBx and regional lymph node dissection (code 3, 4, or 5) in separate surgical events Generally, SLNBx followed by regional lymph node completion will yield a relatively large number of nodes. However, it is possible for these procedures to harvest only a few nodes If relatively few nodes are pathologically examined, review the operative report to confirm whether the procedure was limited to a SLNBx only

9	UNKNOWN OR NOT APPLICABLE	The status of regional lymph node evaluation should be known for surgically treated cases (i.e., cases coded A190-A900 or B190-B900 in the data item <i>Surgery of Primary Site 2023</i> . Review surgically treated cases coded 9 in <i>Scope of Regional</i> <i>Lymph Node Surgery</i> to confirm the code
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Codes (Breast Only):

For all other sites, see <u>Codes (all sites excluding Breast)</u>

Code	Label	Description
0	NO REGIONAL LYMPH NODE SURERY	No regional lymph node surgery
1	BIOPSY OR ASPIRATION OF REGIONAL LYMPH NODE(S)	Excisional biopsy or aspiration of regional lymph nodes for breast cancer is uncommon. Review the operative report to confirm whether an excisional biopsy or aspiration of regional lymph nodes was actually performed; it is highly possible that the procedure is a SLNBx (code 2) instead. If additional procedures were performed on the lymph nodes, such as axillary lymph node dissection, use the appropriate code 2-7
2	SENTINEL LYMPH NODE BIOPSY	If a relatively large number of lymph nodes, more than 5, are pathologically examined, review the operative report to confirm the procedure was limited to a SLNBx and did not include an axillary lymph node dissection (ALND) Infrequently, a SLNBx is attempted, and the patient fails to map (i.e. no sentinel lymph nodes are identified by the dye and/or radio label injection) and no sentinel nodes are removed. Review the operative report to confirm that an axillary incision was made, and a node exploration was conducted. Patients undergoing SLNBx who fail to map will often undergo ALND. Code these cases as 2 if no ALND was performed, or 6 when ALND was performed during the same operative event. Enter the appropriate number of nodes examined and positive in the data items <i>Regional Lymph Nodes</i> <i>Examined</i> and <i>Regional Lymph Nodes Positive</i>
3	NUMBER OF REGIONAL LYMPH NODES REMOVED UNKNOWN OR NOT STATED; REGIONAL LYMPH NODES REMOVED, NOS	Generally, ALND removes at least 7-9 nodes. However, it is possible for these procedures to remove or harvest fewer nodes. Review the operative report to confirm that there was not a SLNBx in addition to a more extensive regional lymph node dissection during the same procedure (code 6 or 7)
4	1-3 REGIONAL LYMPH NODES REMOVED	Generally, ALND removes at least 7-9 nodes. However, it is possible for these procedures to remove or harvest fewer nodes. Review the operative report to confirm that there was not a SLNBx in addition to a more extensive regional lymph node dissection during the same procedure (code 6 or 7)

5	4 OR MORE REGIONAL LYMPH NODES REMOVED	Generally, ALND removes at least 7-9 nodes. However, it is possible for these procedures to remove or harvest fewer nodes. Review the operative report to confirm that there was not a SLNBx in addition to a more extensive regional lymph node dissection during the same procedure (code 6 or 7)
6	SENTINEL NODE BIOPSSY AND CODE 3, 4, OR 5 AT THE SAME TIME, OR TIMING NOT STATED	Generally, SLNBx followed by ALND will yield a minimum of 7-9 nodes. However, it is possible for these procedures to harvest fewer (or more) nodes If relatively few nodes are pathologically examined, review the operative report to confirm whether the procedure was limited to a SLNBx, or whether a SLNBx plus an ALND was performed
7	SENTINEL NODE BIOPSY AND CODE 3, 4, OR 5 AT DIFFERENT TIMES	Generally, SLNBx followed by ALND will yield a minimum of 7-9 nodes. However, it is possible for these procedures to harvest fewer (or more) nodes If relatively few nodes are pathologically examined, review the operative report to confirm whether the procedure was limited to a SLNBx only, or whether a SLNBx plus an ALND
9	UNKNOWN OR NOT APPLICABLE	The status of regional lymph node evaluation should be known for surgically treated cases (i.e., cases coded 19- 90 in the data item <i>Surgery of Primary Site 2023</i> Review surgically treated cases coded 9 in <i>Scope of</i> <i>Regional Lymph Node Surgery</i> to confirm the code

VI.2.5 Pathology Report Identifier Data Items

The following data items have replaced the *DXRX Report Identifiers* as of January 1, 2010. The CCR collects pathology report identifiers that correspond to the diagnostic/staging and surgical procedures collected on the abstract.

CCR Specific Coding Instructions:

- Path Reporting Facility ID (1-5)
 - This data item identifies the pathology facility that produced the report.
- Refer to the most current <u>California Reporting Facility Codes</u> lists, located on the CCR website <u>https://www.ccrcal.org/</u>, Registrar Resources, Reporting Cancer in California, Volumes I-V.
 - Lists are presented in both alphabetical and code order.
 - Enter the reporting facility's CCR assigned reporting facility code.
 - This data item replaced CCR data item, DXRX Report Facility ID, and is required.
- Path Report Numbers (1-5)
 - This data item is a unique sequential number assigned by a laboratory to the corresponding pathology report for the case.
 - This data item replaced CCR data item, DXRX Report Number, and is required.
- Path Date Specimen Collected (1-5)

- This data item collects the date and time of the specimen collection for the cancer being reported, not the date read or date the report was typed.
- This data item replaced CCR data item, DXRX Report Date, and is required.
- Enter the date and, if available, the time the specimen was collected.
- Date Format for this field is **YYYY-MM-DDTHH:MM:SS±ZZ:ZZ where:**
 - YYYY for year
 - MM for month
 - DD for day-of-the-month
 - T to separate date from time if time is provided
 - HH for hour (in 24-hour format)
 - MM for minute
 - SS for second
 - ±ZZ:ZZ for the time zone offset in hours and minutes (e.g. +05:00 for 5 hours ahead of UTC, or -05:00 for 5 hours behind UTC)
- Path Report Type (1-5)
 - This data item describes the type of report transmitted to the cancer registry and may need to be classified at the Central Cancer Registry.
 - This data item accommodates information for only one path report.
 - If additional path reports were prepared, enter the path report type(s) in *Path Report Type 2* through *Path Report Type 5*.
 - This data item is required by the CCR.
- Consult your software vendor for specific data entry instructions.

Code	Description
01	Pathology
02	Cytology
03	Gyn Cytology
04	Bone Marrow (biopsy/aspirate)
05	Autopsy
06	Clinical Laboratory Blood Work, NOS
07	Tumor Marker (p53, CD's Ki, CEA, HER2/neu, etc.)
08	Cytogenetics
09	Immunohistochemical Stains
10	Molecular Studies
11	Flow Cytometry, Immunophenotype
98	Other
99	Unknown

VI.3 Radiation Therapy - First Course of Treatment

The "phase" terminology replaced the traditional terms of "regional" and "boost." The initial phase (Phase I) is frequently referred to as the initial plan and a subsequent (Phase II) may be referred to as the boost or cone down. A new phase begins when there is a change in the target volume of a body site, treatment fraction size, modality, or treatment technique. To accommodate this, three phases of radiation can now be documented. The CCR requirement for these data items are: Required by CoC-accredited facilities and as available by non-CoC accredited facilities for cases diagnosed January 1, 2018 and forward.

Source: The <u>Standards for Oncology Registry Entry (STORE)</u>, and <u>STORE</u>, <u>Appendix R</u> - CTR Guide to Coding Radiation Therapy Treatment is to be used for coding instructions and guidelines for all radiation therapy data items. The manual can also be accessed by going to the following URL: https://www.facs.org/quality-programs/cancer-programs/national-cancer-database/ncdb-call-for-data/registry-manuals/

- **Radiation Primary Treatment Volume Phases I-III -** Identify the primary treatment volume or primary anatomic target delivered to the patient during each phase of radiation during the first course of therapy. This data item should be used to indicate the primary target volume, which might include the primary tumor or tumor bed.
- **Radiation to Draining Lymph Nodes Phases I-III -** Items identify any draining lymph nodes treated during radiation. The first phase commonly targets both the primary tumor **and** draining nodes as a secondary site. This data item indicates the draining LNs, if any, that were radiated during that phase of radiation.
- **Radiation Treatment Modality Phases I-III -** Items identify radiation modality administered during each phase of radiation treatment delivered during the first course of treatment. Radiation modality reflects whether treatment was external beam, brachytherapy, a radioisotope or their major subtypes, or a combination of modalities.
- **Radiation External Beam Planning Technique Phases I-III** Items identify the external beam radiation planning technique used to define the target treatment area and/or administer each phase of radiation treatment during the first course of treatment.
- **Dose per Fraction Phases I-III -** Items identify the dose per fraction (treatment session) delivered to the patient in each phase of radiation during the first course of treatment. Radiation therapy is delivered in one or more phases with identified dose per fraction. The unit of measure is centiGray (cGy).
- **Number of Fractions Phases I-III -** These data items identify the number of fractions (treatment sessions) delivered in each phase of radiation during the first course of treatment.
- **Total Dose Individual Phases I-III -** Items identify the total dose delivered in each phase of radiation during the first course of treatment.
- Number of Phases of Rad Treatment to this Volume Item identifies the total number of phases administered to the patient during the first course of treatment. A "phase" consists of one or more consecutive treatments delivered to the same anatomic volume with no change in the treatment technique. Although most courses of radiation therapy are completed in one or two phases (historically, the "regional" and "boost" treatments) there are occasions in which three or more phases are used, most typically with head and neck malignancies.
- **Radiation Course Total Dose** Phases Combined Item identifies the total radiation dose administered to the patient across all phases during the first course of treatment.
- **Radiation Sequence with Surgery -** Code the sequence in which radiation and surgical procedures were performed as part of the first course of treatment.

- **Radiation Treatment Discontinued Early** Item is used to identify patients/tumors whose radiation treatment course was discontinued earlier than initially planned. That is the patients/tumors received fewer treatment fractions (sessions) than originally intended by the treating physician.
- Location of Radiation Treatment Records the location of the facility in which radiation treatment was administered during first course of treatment.
- **Reason for No Radiation** Records the reason the patient did **not** undergo radiation treatment.

VI.3.1 Types of Radiation

The principal types of radiation therapy are the external administration of radioactive beams, implantation of radioactive material, and the internal administration of radioisotopes by other than implantation.

Guidelines:

Symbol	Description
Au ¹⁹⁸	GOLD
Co ⁶⁰	COBALT
Cr ³² PO ₄	PHOSPHOCOL
CrPO ₄	CHROMIC PHOSPHATE
Cs	CESIUM
I ¹²⁵	IODINE
I ¹³¹	IODINE
Ir ¹⁹²	IRIDIUM
P ³²	PHOSPHORUS
Pb ²¹⁰	LEAD
Ra ²²⁶	RADIUM
Rn ²²²	RADON
Ru ¹⁰⁶	RUTHENIUM
Sr ⁹⁰	STRONTIUM
Y ⁹⁰	YTTRIUM

• Radioactive materials include the following:

VI.3.1.1 External Beam Radiation

Radiation is classified as beam when the source of radioactivity is outside the patient, as in a cobalt machine or linear accelerator.

Guidelines:

- Examples of beam radiation:
 - o Betatron
 - o Brachytron

- Cobalt
- Cyclotron
- Grenz ray
- Helium ion or other heavy particle beam
- Linear accelerator (LINAC)
- o MeV
- Neutron beam
- Photon beam
- Proton beam
- Spray radiation
- Stereotactic radiosurgery, such as gamma knife and proton beam
- o X-ray

VI.3.1.2 Radioactive Implants

Record the name or chemical symbol and method of administration of any radioactive material administered by implants, molds, seeds, needles, or intracavity applicators.

Guidelines:

- The following items are types of radioactive implants and should be coded in the <u>Radiation</u> <u>Treatment Modality - Phases I-III</u> data items:
 - Heyman capsules, Fletcher suit, and Fletcher after loader are methods of isotope application.
 - Record High Dose Rate (HDR) and Low Dose Rate (LDR).
 - I-125 treatment for prostate cancer to brachytherapy.
 - Treatment modality to low dose radiotherapy (LDR).
 - Tumor embolization using a radioactive agent or radioactive seeds.

VI.4 Systemic Therapy - First Course of Treatment

Systemic therapy refers to any type of cancer treatment that targets the entire body. *Chemotherapy*, *Hormone* (Endocrine), *Immunotherapy* (Biological Response Modifier), and *Transplant/Endocrine* therapy data items are types of systemic therapy.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Systemic Therapy* data items. Additionally, registrars **must** use <u>SEER*Rx</u>, for coding systemic treatment (i.e. chemotherapy, hormone therapy, and immunotherapy). This applies to cases diagnosed January 1, 2005 and forward.

Standard Setter Differences:

• *Date of Systemic Therapy* - The CCR does not require facilities to collect the *Date of Systemic Therapy* data item. This information is generated at the central registry. This differs from SEER, which instructs coding manually.

CCR Specific Coding Instructions:

• Systemic Therapy data items:

- **Chemotherapy** Includes the use of any chemical to attack or treat cancer tissue, unless the chemical achieves its effect through change of the hormone balance or by affecting the patient's immune system.
- Hormone (Endocrine) Therapy A form of systemic therapy that works to add, block or remove hormones from the body to slow or stop the growth of cancer cells. Report the administration of hormones, anti-hormones, or steroids to attack cancer tissue by changing the patient's hormone balance.
- **Immunotherapy/Biological Response Modifier Therapy (BRM)** A generic term covering everything done to the immune system to alter it or change the host response to a cancer (defense mechanism).
- Transplant/Endocrine Identifies systemic therapeutic procedures administered as part of the first course of treatment. These procedures include bone marrow transplants (BMT) and stem cell harvests with rescue (stem cell transplant), endocrine surgery and/or radiation performed for hormonal effect (when cancer originates at another site), and a combination of transplants and endocrine therapy.

For reporting purposes, endocrine surgery is defined as the total surgical removal of an endocrine gland (both glands or all of a remaining gland in the case of paired glands).

CCR Specific Coding Instructions:

- The *Date Transplant Endocrine* data item is a CCR specific data item and is required to be collected. It is not collected by Standard Setters.
- There is no text data item for transplant/endocrine procedures. Record text information regarding transplants and endocrine procedures <u>*Text*</u> <u>*Immunotherapy*</u>.

VI.5 Other Therapy - First Course of Treatment

Record the definitive cancer-directed treatment that cannot be classified as surgery, radiation, systemic therapy, or ancillary treatment. Also included are all complementary and alternative medicine (CAM) used by the patient in conjunction with conventional therapy or in place of conventional therapy. Information on other therapy is used to describe and evaluate the quality of care and treatment practices.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Other Therapy* data items.

VI.6 Date of Initial RX SEER

Date of Initial RX SEER, also called Date Therapy Initiated records the start date of any type of treatment for this tumor, surgery, chemotherapy, radiation therapy, other types of therapy, or active surveillance. Treatment or decision for active surveillance may be provided at a hospital or non-hospital setting.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Date of Initial RX SEER* data item.

CCR Specific Guidelines:

• The CCR requires that this data item be **manually coded** and transmitted for cases diagnosed January 1, 2024 and forward.

- Background:
 - Prior to 2024, this data item was not required to be collected and transmitted by CCR. It was generated at the central registry by taking the earliest treatment date from all the treatment modalities.

It now must be directly coded so that if *RX Summary* - *Treatment Status* is coded to 2 (Active Surveillance), the date active surveillance was decided can be recorded. This is a new SEER requirement starting with cases diagnosed January, 1 2024 and forward.

• Allowing manual coding of this data item to meet the new SEER requirement was **missed by the CCR** in the 2024 Data Changes. Therefore, *Registrars are not expected* to go back, and correct cases already submitted to the CCR once vendor software has been updated to allow the date to be manually coded.

VI.7 RX Summary - Treatment Status

This data item is used to summarize the status for all treatment modalities. It is used in conjunction with *Date of Initial RX* and/or *Date of 1st Course RX-CoC* and each modality of treatment with their respective date data item to document whether treatment was given or not given, whether it is unknown if treatment was given, or whether treatment was given on an unknown date. Active surveillance (watchful waiting) is also documented. This data item is required by the CCR.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *RX Summary-Treatment Status* data item.

VI.8 Protocol Participation

This CCR Specific data item collects the patient's participation in a protocol study.

Coding Instructions:

- The CCR requires that this data item be collected and transmitted to the CCR for patient's participation in a protocol study. This is effective with cases diagnosed January 1, 2001 and forward.
- Document in <u>*Text Remarks*</u> the protocol study, clinical trial name or ID/number and study arm, as stated in the medical record.

Examples:

- Protocol: SWOG-SO777
- Protocol: NSAPB B-39, RTOG 04313
- Protocol: RTOG-00534
- Protocol: CodeBreak 300: Colorectal Cancer/NCT05198934
- If a patient is on a treatment regimen that follows a protocol, but the patient is not actually enrolled in the study, then this data item does not apply. Assign code 00.

Code	Description
00	NOT APPLICABLE

National Protocols

Code	Description	
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01	NSABP
02	GOG
03	RTOG
04	SWOG
05	ECOG
06	POG
07	CCG
08	CALGB
09	NCI
10	ACS
11	NATIONAL PROTOCOL, NOS
12	ACOS-OG
13	VA [Veterans Administration]
14	COG (Children's Oncology Group]
15	CTSU [Clinical Trials Support Unit]
16-50	NATIONAL TRIALS

Locally Defined

Code	Description
51-79	LOCALLY DEFINED
80	PHARMACEUTICAL
81-84	LOCALLY DEFINED
85	IN-HOUSE TRIAL
86-88	LOCALLY DEFINED
89	OTHER
90-98	LOCALLY DEFINED
99	UNKNOWN

Part VII. Follow-Up

Part VII of Volume I covers patient and tumor follow-up. It provides resources for where to obtain follow-up information while abstracting. There are guidelines and instructions for collecting data items such as patient contact information, date of last contact, vital status, tumor status, and physician information.

VII.1 Follow-Up Information

A function of the California cancer reporting system is annual monitoring of patients to ascertain survival rates. Therefore, if follow-up information is available before an abstract is submitted, include the follow-up information in the abstract.

Guidelines:

- The CCR requires facilities to use the Modified Record instead of the former Update/Correction and Follow-Up Records to transmit data modifications for abstracts already submitted as New Case Records. See <u>Modified Record</u> for more information.
- Facilities with cancer programs approved by ACS must update follow-up data annually (consult ACS Guidelines for requirements).
- Annual follow-up is not required for a reporting facility that does not have a tumor registry and is submitting an abstract only to meet state reporting requirements. The CCR does not impose follow-up requirements beyond what a hospital chooses to do for its own purposes.

Example: A reporting facility elects not to follow non-analytic cases; the CCR will not expect to receive follow-up information for such cases.

- Additionally, regional registries may obtain further follow-up information using the following methods:
 - Registrar of voters
 - Welfare agencies
 - Labor unions
 - Religious groups
 - Death certificate

Current Follow-Up Information:

- Defined as contact with the patient within 15 months of the date of last reported follow-up.
- Although current follow-up information is preferred, any information, whether current or not, should still be reported.

Site-Specific Follow-up:

- Follow-up is required for the following tumors, although they are categorized in <u>*Class of Case*</u> 34 or 36. This applies to cases diagnosed January 1, 2010 and forward.
 - Benign and borderline CNS tumors diagnosed between January 1, 2001 and December 31, 2003 (before the national benign and borderline CNS tumor reporting requirement was implemented).
 - VIN III
 - VAIN III
 - o AIN III

Shared Follow-Up:

- In those cases, where a patient is being followed by more than one reporting facility, the Regional or the central registry may designate a facility responsible for follow-up in an effort to prevent physicians and patients from receiving requests for information from many sources.
- Shared follow-up which discloses the source or name of the facility requires a signed agreement from each participating registry.
- Follow-up may be shared without a signed agreement as long as the source is not disclosed.
- This does not preclude a facility's registry from submission of more current information about its patients. Shared follow-up is instituted only by agreement among participating facilities in a region.

VII.1.1 Required Data - Follow-Up

Some follow-up data items are optional for reporting to the CCR but might be required by the ACS, for shared follow-up involving other institutions, or by the reporting facility for in-house data.

Coding Instructions:

The CCR's required items for follow-up are:

- Date of Last Patient Contact
- Vital Status
- Date Last Tumor Status
- Tumor Status
- Last Follow-up Facility
- Death information

VII.1.2 Sources of Follow-Up Information

Follow-up information must be based on documentation of contact with the patient in one of the following forms:

- Direct response to a letter or phone call to the patient or other contact person
- A report by the patient's physician
- Re-admission to the facility as an inpatient or outpatient
- Death certificate

Note: It might be necessary to trace the patient through such agencies and organizations as the registrar of voters, welfare agencies, labor unions, religious groups, or the Office of the State Registrar for a death certificate.

VII.2 Follow-Up Data Items

Follow-up data items provide information about the outcome of cancers and the results of treatment. A patient's survival time is calculated based on date of diagnosis and date of last contact.

VII.2.1 Date of Last Contact (AKA-Date Last Pt FU)

This data item captures the date the patient was last seen, heard from, or the date of death. It is important for researchers to calculate survival and outcome studies.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Date of Last Contact* data item.

VII.2.2 Vital Status

This data item records the vital status of the patient on the date of last follow-up.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Vital Status* data item.

VII.2.3 Date of Last Cancer (Tumor) Status

This data item captures the date of the last information obtained on the primary cancer (tumor) being followed. It is important because it documents the status on each tumor when the patient has multiple.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Date of Last Cancer (tumor) Status* data item.

VII.2.4 Cancer (Tumor) Status

This data item records the presence or absence of clinical evidence of the patient's cancer (tumor) as of the *Date of Last Cancer Status* (AKA - Date of Last Tumor Status). It is important because it can be used to gauge disease-free survival.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Cancer (Tumor) Status* data item.

VII.2.5 Last Type of Follow-Up

This CCR Specific data item captures the type of follow-up a patient has received.

Coding Instructions:

- There are two data items which are to be used to enter the source of the most recent follow-up information about the patient and the patient's tumor:
 - See <u>Last Type of **Tumor** Follow-Up</u>
 - See <u>Last Type of **Patient** Follow-Up</u>

VII.2.5.1 Last Type of Tumor Follow-Up

This CCR Specific data item is to be used to enter information representing the source of the most upto-date information on the tumor being followed.

Coding Instructions:

• Reporting facilities ordinarily use the codes 00-15.

Follow-up obtained by Reporting Facility from:

Code	Description
00	Admission being reported
01	Readmission to reporting facility
02	Follow-up report from physician
03	Follow-up report from patient
04	Follow-up report from relative
05	Obituary
07	Follow-up report from hospice
08	Follow-up report from other facility
09	Other source
11	Telephone call to any source
12	Special studies
14	ARS (AIDS registry system)

15 Computer match with discharge data

Follow-up obtained by Regional Registry from:

Code	Description
20	Letter to a physician
22	Computer match with Medicare or Medicaid file
23	Computer match with HMO file
25	National death index
26	Computer match with state death tape
29	Computer match, other or NOS
30	Other source
31	Telephone call to any source
32	Special studies
34	ARS (AIDS registry system)
35	Computer match with discharge data
36	Obituary

Follow-up obtained by Central (State) Registry from:

Code	Description
40	Letter to a physician
41	Telephone call to any source
52	Computer match with Medicare or Medicaid file
53	Computer match with HMO file
55	National death index
56	Computer match with state death tape
59	Computer match, other or NOS
60	Other source

Follow-up obtained by reporting facilities usually done by the Regional/Central Registry:

Code	Description
73	Computer match with HMO file
76	Computer match with state death tape

Additional Codes:

Code	Description
99	Source unknown

VII.2.5.2 Last Type of Patient Follow-Up

This CCR Specific data item is to be used to enter the code representing the source of the most up-todate information about the patient being followed.

Coding Instructions:

• Reporting facilities ordinarily use codes 00-16.

Follow-up obtained by reporting facilities from:

Code	Description
00	Admission being reported
01	Readmission to reporting facility
02	Follow-up report from physician
03	Follow-up report from patient
04	Follow-up report from relative
05	Obituary
06	Follow-up report from Social Security Administration or Medicare
07	Follow-up report from hospice
08	Follow-up report from other facility
09	Other source
11	Telephone call to any source
12	Special studies
13	Equifax
14	ARS (AIDS registry system)
15	Computer match with discharge data
16	SSDI match

Follow-up obtained by Regional Registry from:

Code	Description
20	Letter to a physician
21	Computer match with Department of Motor Vehicles file
22	Computer match with Medicare or Medicaid file
23	Computer match with HMO file
24	Computer match with voter registration file
25	National death index
26	Computer match with state death tape
27	Death master file (Social Security)
29	Computer match, other or NOS

30	Other source
31	Telephone call to any source
32	Special studies
33	Equifax
34	ARS (AIDS registry system)
35	Computer match with discharge data
36	Obituary
37	Computer match with change of address service
38	TRW
39	Regional registry follow-up list

Follow-up obtained by Central (State) Registry from:

Code	Description
40	Letter to a physician
41	Telephone call to any source
50	CMS (Center for Medicare & Medicaid Services)
51	Computer match with Department of Motor Vehicles file
52	Computer match with Medicare or Medicaid file
53	Computer match with HMO file
55	National death index
56	Computer match with state death tape
57	Computer match with Medi-Cal
58	Computer match with Social Security death tape
59	Computer match, other or NOS
60	Other source
61	Social Security - SSN
62	Special studies
65	Computer match with OSHPD hospital discharge database
66	Computer match with national change of address file
67	SSA - Epidemiological vital status
68	Property tax linkage
69	State death tape (incremental)

Follow-up obtained by reporting facilities usually done by the Regional/Central Registry:

Code	Description
73	Computer match with HMO file

76	Computer match with state death tape
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Regional Registry (Additional Codes):

Code	Description
80	Social Security Administration
81	Property tax linkage
82	PROBE360
83	SSDI - Internet
84	E-Path
85	Path labs
86	Patient
87	Relative

Additional Codes:

Code	Description
99	Source unknown

VII.2.6 Last Follow-Up Facility

The CCR assigned reporting facility code for the reporting facility or agency that provided the most recent follow-up information.

Coding Instructions:

- Refer to the most current <u>California Reporting Facility Codes</u> lists, located on the CCR website <u>https://www.ccrcal.org/</u>, Registrar Resources, Reporting Cancer in California, Volumes I-V.
 - Lists are presented in both alphabetical and code order.

VII.2.7 Next Type Follow-Up

Record the method of obtaining follow-up information about the patient for the next report.

Coding Instructions:

- If the patient has died, leave the data item blank.
- Foreign residents may be followed at the reporting facility's discretion, in which case do not use code 8.

Code	Description
0	Submit a request for the patient's chart to the reporting facility's medical records department
1	Send a follow-up letter to the patient's physician
2	Send a follow-up letter to the person designated as the contact for the patient

3	Contact the patient or designated contact by telephone
4	Request follow-up information from another facility
5	Follow-up by a method not described above
6	Send a follow-up letter to the patient
7	Patient presumed lost, stop printing follow-up letters
8	Foreign resident, follow-up discontinued or not initiated
9	Do not follow-up (except code 8)

VII.2.8 Follow-Up Physician

Enter the name or code number of the attending physician, not a resident or intern, who is responsible for the patient. See *Physician License Numbers* for instructions about entering codes.

Coding Instructions:

- Enter code 999999999 if there is no *Follow-Up Physician*.
- Enter code 999999999 if the *Follow-Up Physician* is "unknown" or "license number not assigned."
- Enter the physician NPI code in the respective data item if it is available. See *Entering Physician NPI Codes* for further details.

VII.2.9 Date of First Recurrence

This data item records the date of the first recurrence. Recurrence occurs when a patient's primary tumor persisted after a period of complete remission. *Date of First Recurrence* is required if available by the CCR (if the information is obtainable for abstracting, it is required) by CoC-accredited facilities for cases transmitted 1, 2021 and forward.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Date of First Recurrence* data item.

VII.2.10 Type of First Recurrence

This data item identifies the type of first recurrence after a period of documented disease-free intermission or remission. *Type of First Recurrence* is required if available by the CCR (if the information is obtainable for abstracting, it is required) by CoC-accredited facilities for cases transmitted 1, 2021 and forward.

Source: The <u>SEER Program Coding and Staging Manual</u> is to be used for coding instructions and guidelines for the *Type of First Recurrence* data item.

VII.2.11 Place of Death - Country

Place of Death - Country is intended to collect information on the patient's country of death. Consult with your software vendor for possible auto-generation of this data item.

Coding Instructions:

• Enter the code for the Country in which the death occurred.

- <u>SPM-Appendix B Country and State Codes</u>.
- See also *<u>Vital Status</u>*.
 - If the patient is alive, this data item must be blank.

VII.2.12 Place of Death - State

Place of Death - State is intended to collect information on the State of death.

Coding Instructions:

- Enter the abbreviation for the State in which the death occurred. <u>SPM-Appendix B Country</u> <u>and State Codes</u>.
- See also *<u>Vital Status</u>*.
 - If the patient is alive, this data item must be blank.

VII.3 Follow-Up Contact Name/Address File

The *Contact Name/Address File* is for generating follow-up letters to the patient or designated contact(s).

Coding Instructions:

- Space is provided for the name and address of the patient, including state and country, and up to five contacts for information about the patient.
- Enter names and addresses exactly as they are to appear in the heading of the letter, using capital and lower-case letters, punctuation, and special characters like # for number.
- In the *Phone* data item, enter the area code and number without spaces, dashes, or other marks.
 - For Country of residence, see <u>SPM-Appendix B Country and State Codes</u>.
- A supplemental data item has been added which provides the ability to record additional address information such as the name of a place or facility (i.e., a nursing home or name of an apartment complex). This supplemental data item is limited to 60 characters.

VII.3.1 Follow-Up Contact 1

This data item captures the person who will be the contact for follow-up. This data item is usually designated for the patient, however in some circumstances it may be a parent or guardian. It is where patient follow-up letters are sent.

Coding Instructions:

- Enter the patient's name and preceding Mr., Mrs., Ms., or followed by Jr. or Sr. (up to 60 characters and spaces).
- Enter the current address information:
 - Street address or post office box (up to 60 characters and spaces).
 - Current city (up to 50 characters and spaces).
- Two-character Postal Service abbreviation for the state (<u>SPM-Appendix B Country and State</u> <u>Codes</u>).

- Zip code (up to ten characters and spaces).
- Country code (three characters) if the address is outside the United States. If the patient lives within the United States, this data item may be left blank. If the patient is under 18, enter a parent's name and address.
- Addresses in foreign countries may be entered, including foreign postal codes.
- Entry of a telephone number is required for all patients alive at the time the case is abstracted. Include the area code.
- If the telephone number changes at the time of follow-up, it needs to be changed in this data item. If there is no phone, enter all 0's.
- In the *Patient Address Current--Supplemental* data item, record the place or facility (i.e., nursing home or name of an apartment complex) of the patient's current usual residence.
 - If the patient has multiple tumors, the address should be the same.
 - Update this data item if a patient's address changes.
 - This supplemental data item is limited to 60 characters.

VII.3.2 Follow-Up Contacts 2 - 6

If available in the abstracting software, these follow-up contact data items collect the other contacts the patient has listed in their chart (usually on the face sheet). These contacts are not the patient. They are relatives, friends, neighbors, etc.

Coding Instructions:

- Enter the names, addresses, including country, and phone numbers of up to six people designated as contacts for the case.
- The contacts name preceded by Mr., Mrs., Ms., or followed by Jr. or Sr. (up to 60 characters and spaces).
- The current street address or post office box (up to 60 characters and spaces).
- Current city (up to 50 characters and spaces).
 - Two-character Postal Service abbreviation for the state (see <u>SPM-Appendix B Country</u> <u>and State Codes</u>).
- Zip code (up to ten characters and spaces).
- The three-character country code (see <u>SPM-Appendix B Country and State Codes</u>).
- A supplemental follow-up contact data item has been added. This data item provides the ability to store additional address information such as the name of a place or facility, a nursing home, or the name of an apartment complex.

Notes:

- A supplemental follow-up contact data item has been added. This data item provides the ability to store additional address information such as the name of a place or facility, a nursing home, or the name of an apartment complex.
 - It can be used to generate a follow-up inquiry, and must correspond to the other data items in the follow-up contact address.
 - If the patient has multiple tumors, *Follow-Up Contact--Supplemental* should be the same.

• This supplemental data item is limited to 60 characters.

Part VIII. Transmittal of Case Information, Quality Control, Regional, and Facility Specific Information

Part VIII of Volume I include information on transmitting new and modified cases to the CCR. The second portion explains quality control areas such as completeness, accuracy, timeliness. The third portion includes items that are regional specific and facility specific, also called "user data."

VIII.1 Transmittal of Case Information

The process for transmitting cases to the regional registry is specific to each region. Contact your regional registry for regional specific guidelines. General case transmission guidelines are outlined below.

Coding Instructions:

- All cases must be transmitted electronically.
- Cases are to be transmitted via a secure portal.
- Generally, abstracts are submitted when all required information has been entered. See <u>*Timeliness Quality Control.*</u>
- The types of files transmitted include:
 - New Case Abstracts
 - Modified Record: Includes any changes to the original abstract submitted
 - Deleted cases

Note: Software vendors may have options for direct transmission of the abstract to the central registry. If this capability exists, please refer to the vendor for their protocol.

VIII.1.1 Modified Record

The CCR requires facilities to use the Modified Record to transmit data modifications for abstracts already submitted as New Case Records.

Guidelines:

- The Modified Record, record type M, contains the same data items as the New Case Record, record type A.
- The data item *Follow-up Flag* is no longer required as per the 2023 data changes. Unlike the former Update/Correction record, the Modified Record was designed to allow facilities to submit only one latest modified record per updated case in a modified record transmit file, regardless of the number of types of changes made since the case was last included in a new or modified transmit file.

Due to the SEER*DMS migration, the CCR has adopted SEER's interpretation of the data standard for the NAACCR item, Date Case Report Exported, so facility vendor systems shall

now capture the export/transmit date for the original new case abstract and then overwrite this value with the latest modified record export/transmit date thereafter.

• Facility software vendors MUST NOW INCLUDE ONLY ONE LATEST MODIFIED RECORD PER CASE UPDATED in a single modified record transmit file for the latest transmit cycle, regardless of the number and types of changes made since the last transmit cycle.

See the <u>CCR Volume II, Standards for Automated Reporting</u> for additional detailed information.

VIII.1.1.1 Modified Record - Changing Items in an Abstract

Changes or modifications to an abstract already submitted as New Case Records will be submitted as a Modified Record. Some possible reasons for updating an abstract are described in this section.

Coding Instructions:

• The reasons for changes are not limited to first course of treatment.

Example: Diagnostic Confirmation is a data item that can be changed ANY TIME during the patient's course of disease to a lower code.

- To correct coding or abstracting errors found at the facility.
- When clarifications or rule changes retroactively affect the data item coded.
- When better information is available at a later date.

Example: Follow-up on treatment coded as 88 (recommended, unknown if given) and the patient did have treatment. Update the code in the appropriate treatment data item, along with supporting text in the associated text data item.

- The date of diagnosis is confirmed in retrospect to be earlier than the original date abstracted.
- Updates to an abstract may also be made due to feedback from the regional registry (examples below). If these are the ONLY updates to a case, then a Modified record should not be submitted as these changes have already been made in the central registry database. See <u>CCR</u> <u>Volume II, Standards for Automated Reporting</u> for further details.
 - Recoding Audits
 - Re-Abstracting Audits
 - Follow-up information collected by the regional registry and shared with the facility.

VIII.1.2 Deletions

Deletions are cases that are to be, or have been deleted from the database.

Coding Instructions:

- Delete any duplicate records if a case is found to have been abstracted and sent to the Regional or central registry more than once.
 - Deletions cannot be submitted for a case to be re-abstracted under a new reporting facility if the case was previously abstracted under another reporting source.
- Delete a previously reported case if subsequent evidence disproves the presence of cancer, or if what was thought to be a new primary cancer is later found to be a manifestation of an earlier primary cancer.

- All deletions **must** be reported to the Regional or central registry.
 - Mass deletions must be approved by the Regional or central registry in advance.

VIII.2 Quality Control

The California Cancer Registry (CCR) and Regional Registries have procedures for assuring the quality of the data produced by the reporting system.

The CCR has established uniform standards of quality for facility data in three areas:

- Completeness
- Accuracy
- Timeliness

VIII.2.1 Completeness - Quality Control

Completeness is the extent to which all required cases have been reported. The minimum acceptable level of completeness for a reporting facility is 97 percent of expected case counts per year.

VIII.2.2 Accuracy - Quality Control

Accuracy is the extent to which the data submitted has been correctly coded and matches the information in the medical record and have been correctly coded. It encompasses accurate abstracting, correct application of coding rules, text documentation to support codes, and correct entry into and retrieval from the computer.

Guidelines:

Both analytic and non-analytic cases are included in the accuracy rate and are evaluated using the following methods:

1. Computer Edits:

- Computer edits are used to assess the quality of data submitted. The CCR provides a standard set of edits for abstracting software. These edits are performed on data at the time of abstracting. The measure used to evaluate accuracy is the percent of a facility's cases that fail an edit. CCR's cases must pass the inter-data item edits specified the <u>CCR</u> <u>Edits Metafile</u> located on the CCR website: <u>https://www.ccrcal.org/submit-data/cancer-registrars-hospitals-and-facilities/reporting-by-cancer-registrars/</u>
- The CCR's edit set contains a number of edits that require review. After review and confirmation that the abstracted information is correct, a flag must be set so that repeated review is not necessary, and a case can be set to complete. Please follow the instructions provided by your facility's abstracting software vendor for using these flags.
- The central registry is committed to ensuring high quality data in the database. Business rules have been implemented in the database to evaluate coded data items based on predetermined criteria and then auto-correct miscoded data item(s) based on programmed criteria. These rules have been developed by ODS staff at the central registry and have been rigorously tested prior to implementation.

2. Audits:

- Recoding Audits and Focused Audits are performed routinely to evaluate abstracts and determine if codes are accurately reflecting text documentation (and vice versa), to ascertain whether cases have not been reported that should have been, and to identify coding strengths and weaknesses.
 - 1. Recoding Audits occur once per year and focus on a particular primary site and/or disease.
 - 2. Focused Audits occur several times per year and are focused on evaluating one data item or a group of related data items.
 - 3. Both types of audits randomly select cases from different facilities.
- Re-Abstracting audits are another method used to assess accuracy. A sample of cases from each facility is re-abstracted by specially trained personnel. The measure used is the number of discrepancies found in related categories of items.

VIII.2.2.1 Quality Control Checklist for Abstractors

This checklist is being provided to help ensure the abstracts submitted to CCR are of the highest quality.

- Perform procedures a day or so after abstract has been completed.
 - 1. Global view
 - Give the abstract a visual "once over" review.
 - Are any required fields blank?
 - Are all coded data elements supported and verified in text fields?
 - 2. Case information validation
 - Is the class of case supported by the diagnostic and treatment information?
 - Has the correct CoC Accredited flag been selected? (If your software vendor requires this to be manually selected for each case).
 - 3. Demographic information validation
 - Record any unusual situations in "Remarks"
 - City vs county
 - o Name/ethnicity/race/birthplace/sex
 - 4. Diagnostic evaluation data fields validation
 - Is date of diagnosis the earliest documented date? Is there a logical sequence of events from the date of diagnosis to treatment?
 - Is the diagnostic confirmation consistent with the clinical work-up and/or surgical procedures? Sequence number-are other primaries documented in the history and physical exam text or Remarks field?
 - 5. Cancer identification data fields validation
 - Verify primary site/sub-site text vs ICD-O-3 code.
 - Check primary site and laterality-is it a paired site?
 - $\circ \quad Pathology-site/histology/behavior/grade/laterality\\$
 - Is tumor size recorded in text?
 - 6. Staging validation

- Verify the correct Staging system(s) were used for the diagnosis year to assign stage or Site-Specific factors.
- Compare staging elements with pathology text or additional text fields if used, to be sure there is supporting documentation for all staging data including:
 - Tumor size documentation
 - Extent of disease documentation
 - Regional lymph node status; number positive/number examined
 - Involvement of other organs/tissues
 - Metastasis, distant site(s) or distant LNs
 - Site-Specific Factors
- 7. Treatment validation
 - Is there documentation of all first course treatment modalities?
 - Are all treatment dates documented in text?
 - Is date of treatment after date of diagnosis?
- 8. Follow-up/outcome validation
 - Is date of last contact the same date or later than the latest treatment information?
 - o Is disease status logical in relation to stage and treatment?
- 9. Exchange abstracts with a co-worker
 - Can you follow the sequence of events?
 - Can you easily assign codes to their text?

VIII.2.2 Timeliness - Quality Control

Timeliness involves how quickly the reporting facility submits a case to a regional registry or central registry after admission of the patient. Regional registries and the central registry monitor the timeliness of data submitted by facilities.

Guidelines:

- The standard established by the CCR is that 97 percent of cases must be received by the regional registry or central registry within six months of admission and 100 percent must be received within 12 months of admission.
- Although every effort should be made to complete cases before they are transmitted to the regional registry or central registry, it is recognized that some cancer cases undergo treatment later than six-months from the date of admission.
- Submit treatment information in a Modified Record as available.

VIII.3 Regional Data

Use of the *Regional Data* fields is determined by the Regional registry, which designates the codes to be entered.

VIII.4 Extra Facility Information

The *Extra Facility Information* data items (also called user data) are provided for the convenience of the reporting facility, which determines how they are to be used. All the data items may be left blank. The information is not sent to the CCR.

Part IX. Appendices

The Appendices section of Volume I includes a link to the resources and supplemental information for the abstractor to access for specific coding.

Guidelines:

- To access California Cancer Reporting System Standards, Volume I: Abstracting and Coding Procedures, and Appendices A through I below, please see: <u>https://www.ccrcal.org/submit-data/cancer-registrars-hospitals-and-facilities/reporting-by-cancer-registrars/#volumes-anchor</u>
- Appendices included are:
 - Appendix A Patient Notification of Reportable Neoplasm
 - <u>Appendix B Codes for California Counties</u>
 - o <u>Appendix C Residency of Military Personnel</u>
 - Appendix D Spanish Surnames
 - Appendix E Codes for Religions
 - <u>Appendix F Site-Specific Data Items (SSDIs)</u>
 - o <u>Appendix G Data Alerts and Data Memos</u>
 - <u>Appendix H Q-Tips</u>
 - o <u>Appendix I Coding Resources</u>