

# **CDC Patient Centered Outcomes Research**

## **Data Dictionary for Patient Centered Outcomes Research (PCOR) Data Items**

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National Center for Chronic Disease Prevention & Health Promotion  
Division of Cancer Prevention and Control  
Cancer Surveillance Branch**

## **Overview**

The purpose of this document is to define data standards for Patient Centered Outcomes Research (PCOR)-specific data items that will be collected through the CDC's expanding data collection infrastructure of the National Program of Cancer Registries (NPCR). For all variables that are not routinely collected through NPCR and are not defined by NAACCR, this document describes the data items, the cancer site for which these data items will be collected, the codes to be used, and the source(s) of the data items. In addition, for variables included in the PCOR data set that are defined by the NAACCR Standards for Cancer Registries, Volume II, Data Standards and Data Dictionary, this document also includes their definitions, codes, and the cancer site for which the items will be collected.

### **Patient Centered Outcomes Research (PCOR)**

The purpose of the PCOR activities is to collect longitudinal follow-up of 2011 diagnosed cancer cases of the colon, rectum and breast (male and female). Follow-up will include assessment of vital status, disease recurrence, disease progression and additional type of treatment. If you discover first course treatment data that was not previously collected under CER, please collect that information in the relevant CER data variables.

### **Follow-up of NPCR Specialized Registries breast, colon, and rectal cancer cases diagnosed in 2011**

CDC submitted a proposal to HHS for Patient Centered Outcomes Research funds in order to continue the follow-up of breast, colon, and rectal cancer cases for whom detailed treatment data was collected within the NPCR Specialized Registries. Funding was obtained in FY2013 for this continued follow-up. The focus of this new additional data collection is to assess recurrence and progression of cancer as well as the type of any additional treatment (chemotherapy, radiotherapy, surgery). Additionally minimal data will be collected using standard NAACCR rules on diagnosis data and site of any subsequent primary. These data will permit researchers to evaluate the effectiveness of various treatments for these cancer patients using intermediate outcomes (i.e. recurrence, progression) rather than relying solely on mortality data. The results from analyses may substantially alter future treatment recommendations; therefore, it is critical that the information collected be as accurate as possible.

While passive follow-up measures may be used to assist in identifying recurrence or progression as rapidly as possible, active periodic review of medical records and/or physician contact, as well as active searching for additional information, are mandatory parts of this data collection.

Passive methods to identify progression or recurrence may include reports from hospitals or other providers, such as radiotherapy centers, and linkage with hospital discharge or other data sets. These types of reports need follow-up to determine the date of progression or recurrence, and whether there was a documented period with no evidence of disease / NED / disease-free.

Active assessment of disease status is necessary to minimize patients considered lost to follow-up since physician records may contain additional information and to ensure that the most accurate data are collected. Active assessment of disease status includes review of medical charts (physician notes,

radiology reports, pathology reports, etc.) by the registry or specific verification via the provider for each eligible breast, colon, and rectum case.

To aid in collection of this data, appendix one discusses NCCN guidelines for site specific (and stage as appropriate) post treatment surveillance activities to help the abstractor know what to expect in the medical record of these patients. Additionally we have provided example scenarios and a list of ambiguous terms equivalent to “Disease Free”.

Registries will start the follow-up with the cases diagnosed in January 2011 and work their way forward in time to maximize the follow-up time period, to reduce opportunities for loss to follow-up, and to create similar follow up time periods between diagnosis and active review. Active review requires review of the medical chart(s) or other direct communication with the office of the medical care provider in sufficient detail to provide the required information on progression or recurrence. It is NOT recommended that you rely on reports from CoC hospital registries alone. The source of case status ascertainment will also be collected (e.g. via medical chart, physician contact, etc.). The registries should distribute the active follow-up of cases over the time period to spread the work load and also to create similar follow-up dates for all cases (32 months post diagnosis, for example).

### **Timing of follow-up and additional critical instructions**

**Please note that it is requested that registries collect any first course treatment information that is identified but that was not collected during the CER project.**

A minimum of 32 months active follow-up is required and all related PCOR data items should be collected for each case via active follow-up. Passive follow-up can be used to continue follow-up as long as possible. Follow-up should begin with those cases diagnosed in early 2011.

We know that it may be possible for registries to review a medical chart at 32 months, but that the actual last visit for the case was less than 32 months. This is acceptable. The active follow-up (review of records) should extend to at least 32 months for each case.

One method of focusing work on those cases that may be difficult to locate could be:

- Contact providers and verify when the patient was last seen at that provider. This should help identify patients who have visited the physician and for whom records should be available for review versus those for who may require additional searching.

Please note:

- As part of the passive follow-up, recurrence and progression may be identified through different means; however, passive follow-up (reports from CoC hospitals, data linkages) are not expected to be the primary sources of information and should be followed up with documentation or verification.

<i>SUMMARY</i>	
Active Follow-up At least 32 months post 2011 initial diagnosis: date of active follow-up by registry/abstractor	<ul style="list-style-type: none"> <li>PCOR # 8000, ActiveFUDt (<i>last/most recent date of active follow-up</i>)</li> </ul>
<p><b>Estimated date of completion of first course therapy</b></p> <p>Used to put in disease status dates into context. This is meant to be an estimated date (month and year accepted).</p>	<ul style="list-style-type: none"> <li>PCOR # 8001, Comp1stCrsRxStat (<i>provides information on completion of first course therapy</i>)</li> <li>PCOR # 8002, Comp1stCrsRxDt (<i>estimated date of completion of first course therapy, month and year</i>)</li> <li>PCOR # 8003, Comp1stCrsStatusDatSrc (<i>provides source of information on status – lab tests, physical, etc.</i>)</li> </ul>
<p><b>Disease Free / No Evidence of Disease</b></p> <p>Information on patients’ disease free status and dates of <b>first (earliest)</b> and <b>last (most recent)</b> medical evidence of patient disease free status are recorded in these fields. <u>Do not skip</u> these questions; there are opportunities in the status variables to record if a patient was never disease free. Dates cannot be left blank, 9’s are required if no date is applicable.</p>	<ul style="list-style-type: none"> <li>PCOR # 8004, DsFreeStatus (<i>indicates if the patient ever had a documented disease free status</i>)</li> <li>PCOR # 8005, FrstDsFreeDt (<i>first / earliest date after treatment that “disease free” status is noted</i>)</li> <li>PCOR # 8006, FrstDsFreeDatSrcUsd (<i>provides source of information on status – lab tests, physical, etc.</i>)</li> <li>PCOR # 8007, AddnlDsFreeStatus (<i>indicates if patient had multiple records reporting disease free status</i>)</li> <li>PCOR # 8008, LstDsFreeDt (<i>latest / most recent date that there were indications that patient was disease free</i>)</li> <li>PCOR # 8009, AddnlDsFreeDatSrcUsd (<i>provides source of information on status – lab tests, physical, etc.</i>)</li> </ul>
<p><b>Recurrence, Progression, or Residual Disease</b></p> <p>These variable fields are used to collect information on recurrence, progression and residual disease. <u>Do not skip</u> these questions; there are opportunities to record not applicable status.</p>	<ul style="list-style-type: none"> <li>PCOR # 8010, RecStatus (<i>indicates if the patient ever had a documented recurrence</i>)</li> <li>PCOR # 8011, FrstRecDt (<i>first date where medical evidence indicates recurrence</i>)</li> <li>PCOR # 8012, TypeOfRecurrence (<i>detailed variable on recurrence</i>)</li> <li>PCOR # 8013, RcrDatSrc (<i>medical evidence of recurrence based on physical, lab tests, imaging, etc.</i>)</li> <li>PCOR # 8014, ProgResidDsStatus (<i>indicates if patient progressed during or after first course therapy or had residual disease after completion of first course therapy</i>)</li> <li>PCOR # 8015, ProgressionDt (<i>date where medical evidence indicates progression or residual disease</i>)</li> <li>PCOR # 8016, ProgResidDatSrcUsd (<i>medical evidence of recurrence based on physical, lab tests, imaging, etc.</i>)</li> </ul>

<p><b>Subsequent Primary</b> Describes recorded medical evidence of subsequent primary cancers relative to the patients 2011 colon, breast, or rectal cancer.</p>	<ul style="list-style-type: none"> <li>• PCOR # 8017, SubseqPrmryStatus, (<i>records evidence and site of subsequent tumors</i>)</li> <li>• PCOR #8018, SubseqPrmryDt (<i>first / earliest date where subsequent primary mentioned</i>)</li> <li>• PCOR #8019, SubseqPrmryDatSrcUsd (<i>medical evidence of recurrence based on physical, lab tests, imaging, etc.</i>)</li> </ul>
<p><b>Subsequent treatment for primary</b> (Yes, No, Unknown for each type)</p> <p><i>For PCOR 8022-8026, states may record more detailed information mimicking CER codes provided (these will be indented and italicized)</i></p>	<ul style="list-style-type: none"> <li>• PCOR #8020, PCOR_SubseqRx2ndCrSDt</li> <li>• PCOR #8021, PCOR_SubseqRx2ndCrSDtFlag</li> <li>• PCOR #8022, PCOR_SubseqRx2ndCrSurg</li> <li>• PCOR #8023, PCOR_SubseqRx2ndCrRad</li> <li>• PCOR #8024, PCOR_SubseqRx2ndCrChemo</li> <li>• PCOR #8025, PCOR_SubseqRx2ndCrBRM</li> <li>• PCOR #8026, PCOR_SubseqRx2ndCrOther (non-hormone therapy)</li> </ul>
<p><b>Vital status</b> Standard NAACCR data items. No special instructions for coding.</p>	<ul style="list-style-type: none"> <li>• NAACCR # 1760, Vital Status</li> <li>• NAACCR # 1750, Date of Last Contact</li> <li>• NAACCR # 1751, Date of Last Contact Flag</li> <li>• NAACCR # 1791, Follow-up Source Central</li> </ul>

**Active Follow-Up Date  
(Item # 8000)**

Alternate Name	Item #	Length	Source of Standard	Column #
ActiveFUDt	8000	8	CDC/PCOR	5065-5072

**Cancer Site**

Breast, Colon, and Rectum

**Description**

This variable is used to code the latest date in which abstractors conducted active follow up for the patient. Active follow up requires that the abstractors go beyond receiving COC hospital cancer registry reports and that (abstractors) check hospital, physician office, and non-hospital/non-physician offices sources (including independent/non-hospital based pathology laboratories). This date should be a minimum of 32 months post diagnosis.

**Coding Instructions**

The date format (YYYYMMDD) specifically addresses the NAACCR standard data transmission format; not how the data should be stored in an individual registry's database or viewed on the screen.

**Format**

YYYYMMDD

The field is fixed-length and left-justified.

**Coding**

*See above format instructions from NAACCR Standards for Cancer Registries, Volume II: Data Standards and Data Dictionary, Fifteenth Edition, page 97 for date format.*

***Complete date must be entered; Blanks, 9's /Unknown may not be entered for this variable.***

**Completion 1<sup>st</sup> Course Therapy Status  
(Item # 8001)**

Alternate Name	Item #	Length	Source of Standard	Column #
Comp1stCrsRxStat	8001	1	CDC/PCOR	1348-1348

**Cancer Site**

Breast, Colon, and Rectum

**Description**

This variable is used to code the status of completion of first course therapy (excluding use of hormonal therapy or biologic response modifiers used to reduce risk of recurrence). This information will be used to establish an understanding of whether or not the patient may have completed first course therapy and how this relates to information on known disease status collected later.

NOTE: For the purposes of the PCOR

**Coding Instructions****Coding**

- 0 N/A - No information on patient other than a diagnosis of cancer (lost to follow-up).
- 1 Patient completed 1<sup>st</sup> course therapy (excluding hormonal therapy or biologic response modifiers used to reduce risk of recurrence, i.e. Soltamox/Tamoxifen and Herceptin/Trastuzumab).
- 2 Pt never completed 1<sup>st</sup> course therapy (excluding hormonal therapy or biologic response modifiers used to reduce risk of recurrence), i.e. patient still receiving 1<sup>st</sup> course therapy.
- 3 First course therapy declined or stopped prior to completion by the patient, the patient's family member, or the patient's guardian.
- 4 First course therapy terminated by physician prior to completion (progression or inadequate response).
- 5 Patient died prior to completion of first course therapy
- 9 Unknown. It is uncertain if patient completed first course therapy. *Should be used when patient known to either begin 1<sup>st</sup> course treatment but then is lost to follow-up, or received 1<sup>st</sup> course treatment out of state and are unable to obtain record of treatment.*

**Completion 1<sup>st</sup> Course Therapy Date  
(Item # 8002)**

Alternate Name	Item #	Length	Source of Standard	Column #
Comp1stCrsRxDt	8002	8	CDC/PCOR	5073-5080

**Cancer Site**

Breast, Colon, and Rectum

**Description**

This variable is used to code the ESTIMATED DATE of completion of first course therapy (excluding use of hormonal therapy). This information will be used to establish an understanding of when a patient may have completed first course therapy and how this relates to information on known disease status collected later.

NOTE: For the purposes of the PCOR we are not relying on diagnosis date or date of surgery alone to calculate survival but are attempting to put in the context of survival length after completion of first course therapy (obtaining information on completion of adjuvant chemotherapy and other first course therapies excluding hormonal therapy gives us this ability).

**Coding Instructions**

The date format (YYYYMMDD) specifically addresses the NAACCR standard data transmission format; not how the data should be stored in an individual registry's database or viewed on the screen.

**Every effort must be made to collect, at a minimum, the estimated month and year.**

YYYYMMDD – when year, month and day are known and valid

9's can be used when no date can be estimated (patient did not complete first course of treatment)

Any missing date component should be replaced by 9s.

*Note: Year only should not be used.*

The field is fixed-length and left-justified. If there are no known date components, the fixed-length variable will be 99999999.

**Completion of First Course Therapy Status Data Sources Used  
(Item # 8003)**

Alternate Name	Item #	Length	Source of Standard	Column #
Comp1stCrStatusDatSrc	8003	1	CDC/PCOR	1326-1326

**Cancer Site**

Breast, Colon, and Rectum

**Description**

This variable is used to code the source(s) from which confirmation of the patient's completion of first course therapy (or lack thereof) was obtained.

**Rationale**

This item will help registries and researchers know the location from which information on the patient's status was collected and help assess the breadth of medical documentation available through active surveillance to determine this information. *(Please note that, while we anticipate the vast majority of cases will fit into code 5, being able to identify when cases do not fit into code 5 will be useful to researchers using the data set. If lost to follow-up should document what sources were used prior to patient being lost – i.e. if patient reported by pathology laboratory only and no other information can be found then select option 4.)*

**Coding Instructions**

Select the best code based upon the sources from which active follow up was completed.

**Coding Instructions**

Use the following codes to specify the source from which the patient's cancer status was determined as of the first round of active follow up.

- 0 N/A – No documentation other than a diagnosis of cancer (lost to follow-up).
- 1 COC hospital cancer registry reporting only *(note: relying only on reports from COC hospitals is NOT recommended)*
- 2 Hospital-only documents and files
- 3 Physician-office only sources
- 4 Non-hospital/non-physician office only sources (including independent/non-hospital based pathology laboratories, out of state case sharing, etc.)
- 5 A combination of sources 2-4 with or without CoC registries

**Documented Disease Free Status  
(Item # 8004)**

<b>Alternate Name</b>	<b>Item #</b>	<b>Length</b>	<b>Source of Standard</b>	<b>Column #</b>
DsFreeStatus	8004	1	CDC/PCOR	1327-1327

**Cancer Site**

Breast, Colon, and Rectum

**Description**

This variable is used to indicate if the patient ever had a documented disease free / no evidence of disease status. Information recorded here should correspond with one of the following: history and physical, labs or imaging used to determine disease status. Please note that the laboratory tests or scans can include (but are not limited to): blood tests, liver tests, mammogram, CT scans, colonoscopy, MRI, bone scan, chest imaging, biopsy, etc.).

**Coding**

- 0 No information on patient other than a diagnosis of cancer.
- 1 Patient never found to be disease free (includes those with residual disease, progression, and those who may have died prior to being disease free).
- 2 Patient had at least one record of documented disease free status.
- 9 Unknown. It is unclear in patient record if ever disease free.

**First (earliest) Documented Disease Free Date  
(Item # 8005)**

Alternate Name	Item #	Length	Source of Standard	Column #
FrstDsFreeDt	8005	8	CDC/PCOR	5081-5088

**Cancer Site**

Breast, Colon, and Rectum

**Description**

This variable is used to code the **first (earliest) date** that the patient was determined to be disease free. This date should correspond with one of the following: history and physical, labs or imaging used to clinically evaluate cancer status reported in variable #8004. Please note that the laboratory tests or scans can include (but are not limited to): blood tests, liver tests, mammogram, CT scans, colonoscopy, MRI, bone scan, chest imaging, biopsy, etc.).

The date can correspond with whatever evidence appears to have been used to make the note in the medical record and does not need to correspond to a hierarchy of definitive sources (e.g., if a physician noted “disease free” based on H&P, and later confirmed via a laboratory test, the date of the H&P is still the corresponding date).

*Note: Although many research papers choose either the date of diagnosis or the date of surgery as the start date in survival analysis, we would like the first date where the patient is documented as having no evidence of disease (NED). This may not occur until patient has had some post treatment follow-up such as a CT scan or serial CEA's.*

**Coding Instructions**

Use date format YYYYMMDD to record the earliest date associated with evidence of disease progression or of the patient being considered disease free (no clinical evidence of disease, disease free; in remission)

**Format**

YYYYMMDD when complete date is known and valid

9's should be used when the date is unknown or the patient was never disease free.

Any missing date component should be replaced by 9s.

Year only should not be recorded.

The field is fixed-length and left-justified.

**Coding**

9's may be used when not documented to ever be disease free.

**First (earliest) Disease Free Status Data Sources Used  
(Item # 8006)**

Alternate Name	Item #	Length	Source of Standard	Column #
FrstDsFreeDatSrcUsd	8006	1	CDC/PCOR	1328-1328

**Cancer Site**

Breast, Colon, and Rectum

**Description**

This variable is used to code the source(s) from which confirmation of the patient's first disease free cancer status (**or lack thereof**) was obtained.

**Rationale**

This item will help registries and researchers know the location from which information on the patient's status was collected and help assess the breadth of medical documentation available through active surveillance to determine this information. *(Please note that, while we anticipate the vast majority of cases will fit into code 5, being able to identify when cases do not fit into code 5 will be useful to researchers using the data set.)*

**Coding Instructions**

Select the best code based upon the sources from which active follow up was completed.

**Coding Instructions**

Use the following codes to specify the source from which the patient's cancer status was determined as of the first round of active follow up.

- 0 N/A – No documentation other than a diagnosis of cancer (lost to follow-up).
- 1 COC hospital cancer registry reporting only *(note: relying only on reports from COC hospitals is NOT recommended)*
- 2 Hospital-only documents and files
- 3 Physician-office only sources
- 4 Non-hospital/non-physician office only sources (including independent/non-hospital based pathology laboratories, out of state case sharing, etc.)
- 5 A combination of sources 2-4 with or without CoC registries

**Additional Disease Free Status  
(Item # 8007)**

Alternate Name	Item #	Length	Source of Standard	Column #
AddnlDsFreeStatus	8007	1	CDC/PCOR	1329-1329

**Cancer Site**

Breast, Colon, and Rectum

**Description**

This variable is used to further describe the patients recorded disease free status. This information should be based on one or more of the following: history and physical, labs or imaging used to clinically evaluate cancer status. Please note that the laboratory tests or scans can include (but are not limited to): complete blood count, liver tests, mammogram, CT scans, colonoscopy, MRI, bone scan, chest imaging, biopsy, etc.).

**Coding**

- 0 N/A – No information on patient other than a diagnosis of cancer, patient never found to be disease free (residual disease or progression, Item #8005), or unclear in patient record if ever disease free.
- 1 Patient had multiple documented encounters on different dates in medical record and had no evidence of disease through completion of active follow-up for this patient (the first / earliest recorded disease free date recorded in Item #8005)
- 2 Patient had two or more disease free encounters (the first / earliest recorded in Item #8005) documented in medical record but eventually had documented recurrence.
- 3 Patient found to be disease free (Item #8005 complete) but only one record of being disease free no additional medical records found – lost to follow-up
- 4 Patient found to be disease free but only one record of being disease free (Item #8005 complete) but next patient record found recurrence
- 9 Unknown. Patient was disease free (Item #8005 completed) and additional patient documentation exists, however it is unclear if remained disease free.

**Last (most recent) Disease Free Date  
(Item # 8008)**

Alternate Name	Item #	Length	Source of Standard	Column #
LstDsFreeDt	8008	8	CDC/PCOR	5089-5096

**Cancer Site**

Breast, Colon, and Rectum

**Description**

This variable is used to code the last (most recent/most current) date the patient was considered disease free. This may be the same as the earliest disease free date (i.e. when no additional information is available or a patient is noted to have recurrence on the next encounter). This date should correspond with one or a combination of the following: history and physical, labs or imaging used to clinically evaluate cancer status reported in variable #8007. Please note that the laboratory tests or scans can include (but not limited to): complete blood count, liver tests, mammogram, CT scans, colonoscopy, MRI, bone scan, chest imaging, biopsy, etc.). The date can correspond with whatever evidence appears to have been used to make the note in the medical record and does not need to correspond to a hierarchy of definitive sources.

*NOTE: A series of H & P's, lab studies and imaging studies may be part of a recommended surveillance plan where the disease status and date should be assessed from the collection of these as a group (a cluster of appointments and tests). See the following examples and Appendix One for further information.*

**Examples:**

- 1) If a patient had a medical appointment where the physician noted “No Evidence of Disease / NED” based on physical exam but ordered a colonoscopy and CT scan which were completed one week later and were negative, **the date of the most recent test/study should be used.**
- 2) However if a patient had a medical appointment where the physician noted “No Evidence of Disease / NED” based on physical exam but ordered a colonoscopy and CT scan where one of them was positive for recurrence, *none of these dates should be used as last (most recent) disease free since they were part of a surveillance grouping.* In this case the group of tests and appointments **prior to this would be used as the last (most recent) disease free date.**

This item differs from the standard NAACCR date of last contact variable in that it is not updated based on sources other than clinical data. While the standard NAACCR variable date of last contact can be updated based on linkages to a variety of databases (including department of motor vehicles, NDI, etc.), this date must correspond to active follow up of clinical sources for the PCOR study.

**Coding Instructions**

Use date format YYYYMMDD to record the latest/most recent date associated with evidence of the patient being considered disease free (see guidance above for a cluster of appointments or tests)

**Format**

YYYYMMDD when complete date is known and valid

9's could be used when the date is unknown or never disease free

Any missing component should be replaced by s9's. Year only should not be recorded.

The field is fixed-length and left-justified.

**Coding**

**Note:** 9's may be used when not documented to ever be disease free.

**Additional Disease Free Status Data Sources Used**  
**(Item # 8009)**

Alternate Name	Item #	Length	Source of Standard	Column #
AddnlDsFreeDatSrcUsd	8009	1	CDC/PCOR	1330-1330

**Cancer Site**

Breast, Colon, and Rectum

**Description**

This variable is used to code the source(s) from which confirmation of the patient's additional disease free cancer status and date (**or lack thereof**) was recorded.

**Rationale**

This item will help registries and researchers know the location from which information on the patient's status was collected and help assess the breadth of medical documentation available through active surveillance to determine this information. *(Please note that, while we anticipate the vast majority of cases will fit into code 5, being able to identify when cases do not fit into code 5 will be useful to researchers using the data set.)*

**Coding Instructions**

Select the best code based upon the sources from which active follow up was completed.

**Coding Instructions**

Use the following codes to specify the source from which the patient's cancer status was determined as of the first round of active follow up.

- 0 N/A - No documentation other than a diagnosis of cancer (lost to follow-up).
- 1 COC hospital cancer registry reporting only *(note: relying only on reports from COC hospitals is NOT recommended)*
- 2 Hospital-only documents and files
- 3 Physician-office only sources
- 4 Non-hospital/non-physician office only sources (including independent/non-hospital based pathology laboratories, out of state case sharing, etc.)
- 5 A combination of sources 2-4 with or without CoC registries

**Recurrence Status**  
**(Item # 8010)**

Alternate Name	Item #	Length	Source of Standard	Column #
RecStatus	8010	1	CDC/PCOR	1331

**Cancer Site**

Breast, Colon, and Rectum

**Description**

This variable is used to further describe any recorded evidence of recurrence (this means there was a disease free period before the cancer reappeared -- not residual disease or progression). This information should be based on one of the following: history and physical, labs or imaging used to clinically evaluate cancer status. Please note that the laboratory tests or scans can include (but are not limited to): blood tests, liver tests, mammogram, CT scans, colonoscopy, MRI, bone scan, chest imaging, biopsy, etc.).

**Coding**

- 0 Patient never found to be disease free (for example if patient progressed, has residual disease, lost to follow-up after diagnosis, or died prior to becoming disease free and therefore not able to have a recurrence).
- 1 Found to be disease free and remained disease free till end of study.
- 2 Documented recurrence (after a documented status of disease free / no evidence of disease / NED)
- 3 Uncertain if recurrence or residual disease based on incomplete documentation.
- 4 Uncertain if recurrence or residual disease based on conflicting documentation (one provider reports recurrence and another reports residual disease).
- 9 Unknown. Patient was disease free (Item #8005complete) and additional patient documentation exists, however it is unclear if remained disease free or recurred.

**First Recurrence Date  
(Item # 8011)**

Alternate Name	Item #	Length	Source of Standard	Column #
FrstRecDt	8011	8	CDC/PCOR	5097-5104

**Cancer Site**

Breast, Colon, and Rectum

**Description**

This variable is used to code the **first** date where there was evidence of recurrence (this means there was a disease free / no evidence of disease period before the cancer reappeared -- not residual disease or progression). This date should correspond with one of the following: history and physical, labs or imaging used to clinically evaluate cancer status reported in PCOR variable #8010. Please note that the laboratory tests or scans can include (but are not limited to): blood tests, liver tests, mammogram, CT scans, colonoscopy, MRI, bone scan, chest imaging, biopsy, etc.).

The date can correspond with whatever evidence appears to have been used to make the first note in the medical record of recurrence and does not need to correspond to a hierarchy of definitive sources (e.g., if a physician noted “recurrence” based on H&P, and later confirmed via a laboratory test, the date of the H&P is still the corresponding date).

**Coding Instructions**

Use date format YYYYMMDD to record the earliest date associated with the first recurrence of the primary tumor.

**Format**

YYYYMMDD when complete date is known and valid

9s should be used when the date is unknown or no known date applies

Any missing component should be replaced by 9's

Year only should not be recorded.

The field is fixed-length and left-justified.. If there are no known date components, the fixed-length variable will be filled with eight 9's.

**Coding**

Note: 9's may be used when not documented to ever be disease free.

## Type of Recurrence (Item # 8012)

Alternate Name	Item #	Length	Source of Standard	Column #
TypeOfRecurrence	8012	2	CDC/PCOR	1332-1333

### Cancer Site

Breast, Colon, and Rectum

### Description

Recurrence Type First

This variable is similar to standard NAACCR variable 1880 Type of First Recurrence, but has been revised to specific PCOR standards. The PCOR specific variable serves the following purposes: 1) collapses information from COC hospitals collected via NAACCR data item 1880 into broader categories; 2) defines broader categories for collection of information from non-COC facilities, and 3) creates one variable that will be consistent in how recurrence is define across PCOR collaborators. For registries collecting this information via COC hospitals that use standard NAACCR item 1880, a cross-walk file that converts codes in NAACCR item 1880 to codes in PCOR item 8008 is on the following page.

### Coding

Code for the type of first recurrence after a period of documented disease free intermission or remission.

00	Patient became disease free after treatment and has not had a recurrence
01	In situ recurrence
10	Local recurrence
20	Regional recurrence, NOS
21	Regional recurrence (adjacent tissues or organs)
22	Regional lymph node (LN) recurrence
25	Regional tissue/organ and Regional LN
30	Local and Regional (either LN or tissue/organ) Recurrence
40	Distant recurrence
70	Patient never disease free (residual disease, progression, or death).
88	Recurrence, type unknown
99	Unknown if recurrence or if patient was ever disease free (unclear / conflicting reports in medical record or lost to follow-up)

### *Conversion Type of First Recurrence: NAACCR Item #1880 to PCOR Item #8012*

NAACCR Item #1880 Code	Definition	CDC/PCOR Item # 8012 Code/Recode	Comment
00	Patient became disease-free after treatment and has not had a recurrence.	00 Patient became disease free and has not had recurrence	
04	In situ recurrence of an invasive tumor.	01 Insitu recurrence	

06	In situ recurrence of an in situ tumor.	01 Insitu recurrence	
10	Local recurrence and there is insufficient information available to code to 13-17. Recurrence is confined to the remnant of the organ of origin; to the organ of origin; to the anastomosis; or to scar tissue where the organ previously existed.	10 Local recurrence	
13	Local recurrence of an invasive tumor.	10 Local recurrence	
14	Trocar recurrence of an invasive tumor. Includes recurrence in the trocar path or entrance site following prior surgery.	10 Local recurrence	
15	Both local and trocar recurrence of an invasive tumor (both 13 and 14)	10 Local recurrence	
16	Local recurrence of an in situ tumor.	10 Local recurrence	
17	Both local and trocar recurrence of an in situ tumor.	10 Local recurrence	
20	Regional recurrence, and there is insufficient information available to code to 21-27.	20 Regional recurrence tissue/organ	
21	Recurrence of an invasive tumor in adjacent tissue or organ(s) only.	21 Regional recurrence	
22	Recurrence of an invasive tumor in regional lymph nodes only.	22 Regional recurrence LN	
25	Recurrence of an invasive tumor in adjacent tissue or organ(s) and in regional lymph nodes (both 21 and 22) at the same time.	25 Regional recurrence LN and tissue/organ	
26	Regional recurrence of an in situ tumor, NOS.	20 Regional recurrence	
27	Recurrence of an in situ tumor in adjacent tissue or organ(s) and in regional lymph nodes at the same time.	20 Regional recurrence	
30	Both regional recurrence of an invasive tumor in adjacent tissue or organ(s) and/or regional lymph nodes (20-25) and local and/or trocar recurrence (10, 13, 14, or 15).	30 Regional and Local Recurrence	
36	Both regional recurrence of an in situ tumor in adjacent tissue or organ(s) and/or regional lymph	30 Regional and	

	nodes (26 or 27) and local and/or trocar recurrence (16 or 17).	Local Recurrence	
40	Distant recurrence and there is insufficient information available to code to 46-62.	40 Distant Recurrence	
46	Distant recurrence of an in situ tumor.	40 Distant Recurrence	
51	Distant recurrence of an invasive tumor in the peritoneum only. Peritoneum includes peritoneal surfaces of all structures within the abdominal cavity and/or positive ascitic fluid.	40 Distant Recurrence	
70	Since diagnosis, patient has never been disease-free. This includes cases with distant metastasis at diagnosis, systemic disease, unknown primary, or minimal disease that is not treated.	70 Residual disease or progression.	
88	Disease has recurred, but the type of recurrence is unknown.	88 Recurrence, Unknown type	
99	It is unknown whether the disease has recurred or if the patient was ever disease-free.	99 Unknown	

**Recurrence Status Data Sources Used  
(Item # 8013)**

Alternate Name	Item #	Length	Source of Standard	Column #
RcrDatSrc	8013	1	CDC/PCOR	1334-1334

**Cancer Site**

Breast, Colon, and Rectum

**Description**

This variable is used to code the source(s) from which confirmation of the patient's recurrence status (**or lack thereof**) was determined.

**Rationale**

This item will help registries and researchers know the location from which information on the patient's status was collected and help assess the breadth of medical documentation available through active surveillance to determine this information. *(Please note that, while we anticipate the vast majority of cases will fit into code 5, being able to identify when cases do not fit into code 5 will be useful to researchers using the data set.)*

**Coding Instructions**

Select the best code based upon the sources from which active follow up was completed.

**Coding Instructions**

Use the following codes to specify the source from which the patient's cancer status was determined as of the first round of active follow up.

- 0 N/A - No documentation other than a diagnosis of cancer (lost to follow-up)
- 1 COC hospital cancer registry reporting only *(note: relying only on reports from COC hospitals is NOT recommended)*
- 2 Hospital-only documents and files
- 3 Physician-office only sources
- 4 Non-hospital/non-physician office only sources (including independent/non-hospital based pathology laboratories, out of state case sharing, etc.)
- 5 A combination of sources 2-4 with or without CoC registries

**Progression / Residual Disease Status  
(Item # 8014)**

Alternate Name	Item #	Length	Source of Standard	Column #
ProgResidDsStatus	8014	1	CDC/PCOR	1335-1335

**Cancer Site**

Breast, Colon, and Rectum

**Description**

This variable is used to further describe any recorded evidence of progression or residual disease (**NOT recurrence**). This information should correspond with one of the following: history and physical, labs or imaging used to clinically evaluate cancer status. Please note that the laboratory tests or scans can include (but are not limited to): blood tests, liver tests, mammogram, CT scans, colonoscopy, MRI, bone scan, chest imaging, biopsy, etc.).

**Coding**

- 0 Patient found to be disease free.
- 1 Patient had partial response to therapy with residual disease (never disease free but not progressed).
- 2 Patient had documented progression during or after completion of first course therapy.
- 3 Patient never disease free but uncertain if progressed or residual.
- 9 Unknown –No information on patient other than a diagnosis of cancer or incomplete medical information (lost to follow-up or died prior to documentation of response to therapy)

**Progression Date  
(Item # 8015)**

Alternate Name	Item #	Length	Source of Standard	Column #
ProgressionDt	8015	8	CDC/PCOR	5105-5112

**Cancer Site**

Breast, Colon, and Rectum

**Description**

This variable is used to code the **first** date where there was evidence of **progression** (not residual disease, no date collected for residual disease) either **during** 1<sup>st</sup> course therapy **or after completion** of 1<sup>st</sup> course therapy. (*Note: Collection of this information is not meant to address pre-treatment progression*). This date should correspond with one of the following: history and physical, labs or imaging used to clinically evaluate cancer status reported in PCOR variable #8014. Please note that the laboratory tests or scans can include (but are not limited to): blood tests, liver tests, mammogram, CT scans, colonoscopy, MRI, bone scan, chest imaging, biopsy, etc.).

The date can correspond with whatever evidence appears to have been used to make the first note in the medical record of progression (if applicable) and does not need to correspond to a hierarchy of definitive sources (e.g., if a physician noted “progression” based on H&P, and later confirmed via a laboratory test, the date of the H&P is still the corresponding date).

**Coding Instructions**

Use date format YYYYMMDD to record the earliest date associated with evidence of disease progression.

**Format**

YYYYMMDD when complete date is known and valid

9’s could be used when the date is unknown or no known date applies

Any missing component should be replaced by s9’s.

Year only should not be recorded.

The field is fixed-length and left-justified. If there are no known date components, the fixed-length variable will be filled with eight 9’s.

**Coding**

Note: 9’s may be used when no disease progression.

**Progression / Residual Disease Status Sources Used  
(Item # 8016)**

Alternate Name	Item #	Length	Source of Standard	Column #
ProgResidDatSrcUsd	8016	1	CDC/PCOR	1336-1336

**Cancer Site**

Breast, Colon, and Rectum

**Description**

This variable is used to code the source(s) from which confirmation of the patient's cancer status (progression / residual disease **or lack thereof**) was determined.

**Rationale**

This item will help registries and researchers know the location from which information on the patient's status was collected and help assess the breadth of medical documentation available through active surveillance to determine this information. *(Please note that, while we anticipate the vast majority of cases will fit into code 5, being able to identify when cases do not fit into code 5 will be useful to researchers using the data set.)*

**Coding Instructions**

Select the best code based upon the sources from which active follow up was completed.

**Coding Instructions**

Use the following codes to specify the source from which the patient's cancer status was determined as of the first round of active follow up.

- 0 N/A - No documentation other than a diagnosis of cancer (lost to follow-up).
- 1 COC hospital cancer registry reporting only *(note: relying only on reports from COC hospitals is NOT recommended)*
- 2 Hospital-only documents and files
- 3 Physician-office only sources
- 4 Non-hospital/non-physician office only sources (including independent/non-hospital based pathology laboratories, out of state case sharing, etc.)
- 5 A combination of sources 2-4 with or without CoC registries

**Subsequent Primary Status  
(Item # 8017)**

Alternate Name	Item #	Length	Source of Standard	Column #
SubseqPrimryStatus	8017	1	CDC/PCOR	1337-1337

**Cancer Site**

Breast, Colon, and Rectum

**Description**

This variable is used to further describe any recorded evidence of a subsequent primary relative to a patients' initial 2011 CER-eligible tumor.

Abstractors should follow Multiple Primary and Histology Coding Rules Manual rules to determine subsequent primary for breast and colon.

**Coding Instructions**

Select the best code based upon documented evidence of the patient's cancer status during active follow up. Data collectors should NOT include information on synchronous primary cancers (cancers diagnosed at the same time in 2011 and within the same primary organ) in this data item.

**Codes**

- 0 N/A – No evidence of subsequent primary.
- 1 Evidence of subsequent primary, same site as initial tumor
- 2 Evidence of subsequent primary, site other than initial tumor
- 3 Evidence of subsequent primary, site unknown
- 9 Unknown. Conflicting documentation of possible subsequent primary versus recurrence or metastasis.

**Subsequent Primary Date  
(Item # 8018)**

Alternate Name	Item #	Length	Source of Standard	Column #
SubseqPrmryDt	8018	8	CDC/PCOR	5113-5120

**Cancer Site**

Breast, Colon, and Rectum

**Description**

This variable is used to code the **first** date where there was evidence of subsequent primary. This date should correspond with one of the following: history and physical, labs or imaging used to clinically evaluate cancer status reported in PCOR variable #8017. Please note that the laboratory tests or scans can include (but are not limited to): blood tests, liver tests, mammogram, CT scans, colonoscopy, MRI, bone scan, chest imaging, biopsy, etc.).

The date can correspond with whatever evidence appears to have been used to make the first note in the medical record of a subsequent primary and does not need to correspond to a hierarchy of definitive sources.

**Coding Instructions**

Use date format YYYYMMDD to record the earliest date associated with evidence of a subsequent primary.

**Format**

YYYYMMDD when complete date is known and valid

9's could be used when the date is unknown or no known date applies

Any missing component should be replaced by 9's

Year only should not be recorded.

The field is fixed-length and left-justified.. If there are no known date components, the fixed-length variable will be filled with eight 9's.

**Coding**

Note: 9's may be used when no documented subsequent primary.

**Subsequent Primary Data Sources Used**  
**(Item # 8019)**

Alternate Name	Item #	Length	Source of Standard	Column #
SubseqPrimryDatSrcUsd	8019	1	CDC/PCOR	1338-1338

**Cancer Site**

Breast, Colon, and Rectum

**Description**

This variable is used to code the source(s) from which confirmation of the patient's cancer status (subsequent primary or lack thereof) was determined.

**Rationale**

This item will help registries and researchers know the location from which information on the patient's status was collected and help assess the breadth of medical documentation available through active surveillance to determine this information. *(Please note that, while we anticipate the vast majority of cases will fit into code 5, being able to identify when cases do not fit into code 5 will be useful to researchers using the data set.)*

**Coding Instructions**

Select the best code based upon the sources from which active follow up was completed.

**Coding Instructions**

Use the following codes to specify the source from which the patient's cancer status was determined as of the first round of active follow up.

- 0 N/A - No documentation other than a diagnosis of cancer (lost to follow-up).
- 1 COC hospital cancer registry reporting only *(note: relying only on reports from COC hospitals is NOT recommended)*
- 2 Hospital-only documents and files
- 3 Physician-office only sources
- 4 Non-hospital/non-physician office only sources (including independent/non-hospital based pathology laboratories, out of state case sharing, etc.)
- 5 A combination of sources 2-4 with or without CoC registries

## Primary Tumor Subsequent Treatment

The following PCOR items (PCOR 8020 through 8026) refer to subsequent therapy given for the primary tumor. These items are similar to the information collected as part of CER (NAACCR Item 1660 and CER item numbers 9955, 9921 – 9923, 9926, and 9926). The CER items were first introduced for the 2011 CER project and may have been completed in two situations:

- 1) Patient had a change to the classification of medication they had been taking as part of their first course therapy
- 2) Patient had a recurrence or progression and had 2<sup>nd</sup> course therapy treating the primary tumor before the end of the CER study period.

Because of this we have created new PCOR data items that mimic the above NAACCR and CER data items to be collected regarding primary tumor subsequent treatment for PCOR purposes only. If data had been entered in CER for scenario 1 above, this information would not be relevant for primary tumor subsequent therapy for recurrence or progression. If however scenario 2 above occurred during CER, that information should be repopulated for these new PCOR data items.

**Please collect 2<sup>nd</sup> course therapies according to current SEER\*Rx classification. An example of this is for Herceptin/Trastuzumab, this should be considered a biologic response modifier (BRM) as it is currently considered and not a chemotherapy medication as it was misclassified in 2011.**

In an attempt to make collection of subsequent therapy easier additional codes have been added to each data item to clearly indicate if the patient did receive subsequent therapy, did not receive subsequent therapy, or if it is unknown.

**For coding purposes** please use the new codes to indicate **not receiving** subsequent therapy or if it is unknown (these codes are 04 or 4 and 99 or 9 respectively depending on the length of the subsequent therapy item).

A code of 05 or 5 (again depending on the item number) should be used to code that the patient **did receive** subsequent therapy unless the state wishes to collect additional detail information regarding the subsequent therapy by using the codes previously established under CER with the exception of 00 or 0. The codes that may be collected for additional detailed information are indented and replicate those collected under CER.

- *The codes that may be collected for additional detailed information are indented.*

**However, under no circumstances should 00 or 0 be coded for item number 8022 through 8026 for the PCOR project.**

**Primary Tumor Subsequent Treatment Start Date  
(Item # 8020)**

Alternate Name	Item #	Length	Source of Standard	Column #
PCOR_SubseqRx2ndCrsDt	8020	8	CDC/PCOR	5121-5128

**Cancer Site**

Breast, Colon, and Rectum

**Description**

Date of initiation of subsequent treatment for **primary tumor**.

Patient's medical records and available pharmacy data sets should be included as potential sources for obtaining this data.

Note: This data item is no longer supported by COC (as of January 1, 2003), but is being collected for the purposes of the PCOR special study.

**Coding Instructions**

Use date format YYYYMMDD to record the earliest date of subsequent treatment associated with evidence of disease progression or recurrence.

**Format**

YYYYMMDD when complete date is known and valid

YYYYMM when year and month are known and valid, and day is unknown

YYYY when year is known and valid, and month and day are unknown

Blank when no known date applies.

The field is fixed-length and left-justified. Any missing component should be replaced by spaces. If there are no known date components, the fixed-length variable will be completely blank.

Coding

**Note:** For SubsqRX2CrsDate 9's may **NOT** be used when no documented subsequent treatment.

**Subsequent Treatment Date Flag CER  
(Item # 8021)**

Alternate Name	Item #	Length	Source of Standard	Column #
PCOR_SubseqRx2ndCrSDtFlag	8021	2	CDC/PCOR	5129-5130

**Cancer Site**

Breast, Colon, and Rectum

**Description**

This flag explains why no appropriate value is in the field, Subsq RX 2<sup>nd</sup> Course Date [1660]. This data item was first available in Volume II Version 12 (effective January 2010).

**Rationale**

Prior to Version 12 (through 2009 diagnosis), date fields included codes that provided information other than dates. As part of an initiative to standardize date fields, new fields were introduced to accommodate non-date information that had previously been transmitted in date fields.

**Codes (see NAACCR data dictionary Appendix H for the complete Flavors of Null table, which includes the NAACCR codes, HL7 codes and definitions).**

- 10 No information whatsoever can be inferred from this exceptional value (e.g., unknown if any subsequent therapy)
- 11 No proper value is applicable in this context (e.g., no subsequent therapy)
- 12 A proper value is applicable but not known. This event occurred, but the date is unknown (e.g., subsequent therapy given, but date is unknown)
- 15 Information is not available at this time, but it is expected that it will be available later (e.g., subsequent therapy ordered, but has not been administered at the time of the most recent follow up)
- Blank A valid date value is provided in item Subsq RX 2<sup>nd</sup> Course Date [1660], or the date was not expected to have been transmitted

### Subsequent Treatment Surgery (Item # 8022)

Alternate Name	Item #	Length	Source of Standard	Column #
PCOR_SubseqRx2ndCrSurg	8022	2	CDC/PCOR	1339-1340

#### Cancer Site

Breast, Colon, and Rectum

#### Description

This variable is used to code if surgery was given as part of the subsequent course of treatment for **primary tumor**. Subsequent treatment is defined as: all cancer-directed therapies administered after the first course is complete due to lack of response or disease progression or recurrence. Therapy administered after the first course is completed, stopped or changed is recorded as subsequent therapy.

Patient's medical records should be included as potential sources for obtaining this data.

Subsequent surgery is a treatment consideration for local, regional or distant recurrence or progression of disease. Subsequent surgery is also a treatment consideration when other planned first course of treatment fails.

#### Codes

04 None

05 Patient had a documented subsequent surgery

10 *Surgery to local site*

20 *Surgery to regional site/lymph nodes*

30 *Surgery to distant site/lymph nodes*

90 *Surgery, NOS; a subsequent surgical procedure was done, but no information on the type of surgical procedure is provided.*

99 Unknown.

Note: States may use the indented codes if you wish to collect more detailed information (10-90). However, if coding the detailed codes please consistently collect the detailed codes for all subsequent treatment variables.

### Subsequent Treatment Radiation (Item #8023)

Alternate Name	Item #	Length	Source of Standard	Column #
PCOR_SubseqRx2ndCrRad	8023	2	CDC/PCOR	1341-1342

#### Cancer Site

Breast, Colon, and Rectum

#### Description

This variable is used to code if radiation therapy was used as subsequent treatment for **primary tumor**. Subsequent treatment is defined as: all cancer-directed therapies administered after the first course is complete due to lack of response or disease progression or recurrence. Therapy administered after the first course is completed, stopped or changed is recorded as subsequent therapy.

Patient's medical records should be included as potential sources for obtaining this data.

Subsequent radiation therapy is a treatment consideration for local, regional or distant recurrence or progression of disease. Subsequent radiation therapy is also a treatment consideration when other planned first course of treatment fails. Subsequent radiation may be administered as part of other subsequent treatments (surgery, chemotherapy, etc).

- Radiation may be localized (at the primary site)
- Radiation may be directed to regional site and/or to regional lymph nodes
- Radiation may be directed to a distant or metastatic site or lymph nodes

#### Codes

04 None

05 Patient had a documented subsequent radiation

*10 Local radiation*

*20 Regional radiation*

*30 Distant radiation, NOS OR other radiation, NOS*

*31 Bone*

*32 Brain*

*33 Liver*

*34 Lung*

*35 Other distant sites/lymph nodes or more than one distant site*

99 Unknown

Note: States may use the indented codes if you wish to collect more detailed information (10-35). However, if coding the detailed codes please consistently collect the detailed codes for all subsequent treatment variables.

## Subsequent Treatment Chemotherapy (Item #8024)

Alternate Name	Item #	Length	Source of Standard	Column #
PCOR_SubseqRx2ndCrSChemo	8024	2	CDC/PCOR	1343-1344

### Cancer Site

Breast, Colon, and Rectum

### Description

This variable is used to code if chemotherapy was given as part of the subsequent course of treatment for **primary tumor**. Subsequent treatment is defined as: all cancer-directed therapies administered after the first course is complete due to lack of response or disease progression or recurrence. Therapy administered after the first course is completed, stopped or changed is recorded as subsequent therapy.

Patient's medical records and available pharmacy data sets should be included as potential sources for obtaining this data.

### Codes

- 01      *Chemotherapy administered as subsequent therapy, but the type and number of agents is not documented in patient record.*
- 02      *Single-agent chemotherapy administered as subsequent therapy.*
- 03      *Multiagent chemotherapy administered as subsequent therapy.*
- 04      None
- 05      Patient had a documented subsequent chemotherapy
- 99      Unknown

Note: States may use the indented codes if you wish to collect more detailed information (01-03). However, if coding the detailed codes please consistently collect the detailed codes for all subsequent treatment variables.

- Refer to the *SEER\*Rx Interactive Drug Database* (<http://seer.cancer.gov/>) for a list of chemotherapeutic agents.
- If the managing physician changed one of the agents in a combination regimen, and the replacement agent belonged to a different group (chemotherapeutic agents are grouped as alkylating agents, antimetabolites, natural products, or other miscellaneous) than the original agent, the new regimen represented the start of subsequent therapy.

### Subsequent Treatment BRM (Item #8025)

Alternate Name	Item #	Length	Source of Standard	Column #
PCOR_SubseqRx2ndCrsBRM	8025	2	CDC/PCOR	1345-1346

#### Cancer Site

Breast, Colon, and Rectum

#### Description

This variable is used to code if any biological response modifier therapy (immunotherapy) was given as part of the subsequent course of treatment for **primary tumor**. Subsequent treatment is defined as: all cancer-directed therapies administered after the first course is complete due to lack of response or disease progression or recurrence. Therapy administered after the first course is completed, stopped or changed is recorded as subsequent therapy.

Patient's medical records and available pharmacy data sets should be included as potential sources for obtaining this data.

#### Coding

Refer to the *SEER\*Rx Interactive Drug Database* (<http://seer.cancer.gov/>) for a list of immunotherapeutic agents.

#### Codes

- 01 *Immunotherapy administered as subsequent therapy.*
- 04 None
- 05 Patient had a documented subsequent BRM
- 99 Unknown

**Subsequent Treatment Other (excluding hormonal therapy)  
(Item #8026)**

Alternate Name	Item #	Length	Source of Standard	Column #
PCOR_SubseqRx2ndCrOther	8026	1	CDC/PCOR	1347-1347

**Cancer Site**

Breast, Colon, and Rectum

**Description**

This variable is used to code if any other treatment was given as part of the subsequent course of treatment (excluding hormonal therapy) for **primary tumor**. Subsequent treatment is defined as: all cancer-directed therapies administered after the first course is complete due to lack of response or disease progression or recurrence. Therapy administered after the first course is completed, stopped or changed is recorded as subsequent therapy.

Patient's medical records and available pharmacy data sets should be included as potential sources for obtaining this data.

**Codes**

- 1      *Other – Subsequent treatment that cannot be appropriately assigned to specified treatment data items (surgery, radiation, and systemic therapy, hematopoietic cases, such as phlebotomy, transfusion, or aspirin).*
- 2      *Other – Experimental This code is not defined. It may be used to record participation in institution-based clinical trials.*
- 3      *Other – Double Blind A patient is involved in a double-blind clinical trial. Code the treatment actually administered when the double-blind trial code is broken.*
- 4      None
- 5      Patient had other documented subsequent treatment (excluding hormone therapy)
  - 6      *Other – Unproven Cancer treatments administered by nonmedical personnel.*
- 9      Unknown.

Note: States may use the indented codes if you wish to collect more detailed information (1-3 and 6). However, if coding the detailed codes please consistently collect the detailed codes for all subsequent treatment variables.

## Date of Last Contact (Item #1750)

### Date of Last Contact

Alternate Name	Item #	Length	Source of Standard	Column #
Date of Last Contact or Death (COC)	1750	8	SEER/COC	2116-2123
Date of Last Follow Up or Death (SEER)				

### Cancer Site

Breast, Colon, and Rectal

### Description

Date of last contact with the patient, or date of death. If the patient has multiple tumors, Date of Last Contact should be the same for all tumors. See Chapter X for date format.

### Rationale

Used for recording Date of Last Contact from active or passive follow-up. Used to record date of death and to calculate survival.

### Coding Instructions

Use date format YYYYMMDD to record the earliest date associated with evidence of disease progression or of the patient being considered disease free (no clinical evidence of disease, disease free; in remission)

### Format

YYYYMMDD when complete date is known and valid

YYYYMM when year and month are known and valid, and day is unknown

YYYY when year is known and valid, and month and day are unknown

Blank when no known date applies (Date of Last Contact Flag must be completed)

The field is fixed-length and left-justified. Any missing component should be replaced by spaces. If there are no known date components, the fixed-length variable will be completely blank.

**Note:** For *Date of Last Contact 9's* may **NOT** be used when no documented subsequent treatment.

**Date of Last Contact Flag  
(Item #1751)**

**Date of Last Contact Flag**

Alternate Name	Item #	Length	Source of Standard	Column #
Date of Last Contact Flag	1751	2	NAACCR	2124-2125

**Cancer Site**

Breast, Colon, and Rectum

**Description**

This flag explains why no appropriate value is in the field, Date of Last Contact [1750]. This data item first available in Volume II Version 12.

**Rationale**

Before Version 12 (through 2009 diagnosis), date fields included codes that provided information other than dates. As part of an initiative to standardize date fields, new fields were introduced to accommodate non-date information that had previously been transmitted in date fields.

**Codes (See Appendix H for the complete Flavors of Null table, which includes the NAACCR codes, HL7 codes and definitions.)**

12 A proper value is applicable but not known. This event occurred, but the date is unknown (e.g., date of last contact is unknown).

Blank A valid date value is provided in item Date of Last Contact [1750], or the date was not expected to have been transmitted.

Comment: This is part of the initiative of the transformation from the old NAACCR date standards to interoperable dates.

**Vital Status  
(Item #1760)**

**Vital Status**

<b>Alternate Name</b>	<b>Item #</b>	<b>Length</b>	<b>Source of Standard</b>	<b>Column #</b>
Vital Status	1760	1	SEER/COC	2126-2126

**Cancer Site**

Breast, Colon, and Rectal

**Description**

Vital status of the patient as of the date entered in Date of Last Contact [1750]. If the patient has multiple tumors, vital status should be the same for all tumors.

**Codes**

- 0 Dead (CoC)
- 1 Alive
- 4 Dead (SEER)

## Follow-up Source Central (Item #1791)

### Follow-up Source Central

SAS Alternate Name	Item #	Length	Source of Standard	Column #
	1791	2	NAACCR	2278-2279

### Description

This field is created by the central registry. It records the source from which the consolidated information was obtained on a patient's vital status and date of last contact. Follow-up Source Central would be updated when new or more reliable information becomes available. However, when the existing date of last contact/vital status is deemed to be more reliable than newly obtained information, then neither the date of last contact/vital status nor the follow-up source central would be changed.

### Rationale

For central registries performing follow-up, this field could help evaluate the success rates of various methods of follow-up. When new follow-up information conflicts with the existing information, knowing the follow-up source can help resolve any discrepancies.

### Codes

00	Follow-up not performed for this patient
(01-29)	File Linkages
01	Medicare/Medicaid File
02	Center for Medicare and Medicaid Services (CMS, formerly HCFA)
03	Department of Motor Vehicle Registration
04	National Death Index (NDI)
05	State Death Tape/Death Certificate File
06	County/Municipality Death Tape/ Death Certificate File
07	Social Security Administration Death Master File
08	Hospital Discharge Data
09	Health Maintenance Organization (HMO) file
10	Social Security Epidemiological Vital Status Data
11	Voter Registration File
12	Research/Study Related Linkage
29	Linkages, NOS
(30-39)	Hospitals and Treatment Facilities
30	Hospital in-patient/outpatient
31	Casefinding
32	Hospital cancer registry
33	Radiation treatment center
34	Oncology clinic
35	Ambulatory surgical center
39	Clinic/facility, NOS
(40-49)	Physicians
40	Attending physician
41	Medical oncologist
42	Radiation oncologist
43	Surgeon

48	Other specialist
49	Physician, NOS
(50-59)	Patient
50	Patient contact
51	Relative contact
59	Patient, NOS
(60-98)	Other
60	Central or Regional cancer registry
61	Internet sources
62	Hospice
63	Nursing homes
64	Obituary
65	Other research/study related sources
98	Other, NOS
99	Unknown source

**Reference**

Thornton M, (ed). *Standards for Cancer Registries Volume II: Data Standards and Data Dictionary, Record Layout Version 12.1*, 15<sup>th</sup> ed. Springfield, Ill.: North American Association of Central Cancer Registries, June 2010.

<http://www.naaccr.org/LinkClick.aspx?fileticket=LJJNRVo4IT4%3D&tabid=268&mid=746>