PATIENT LEVEL DATA

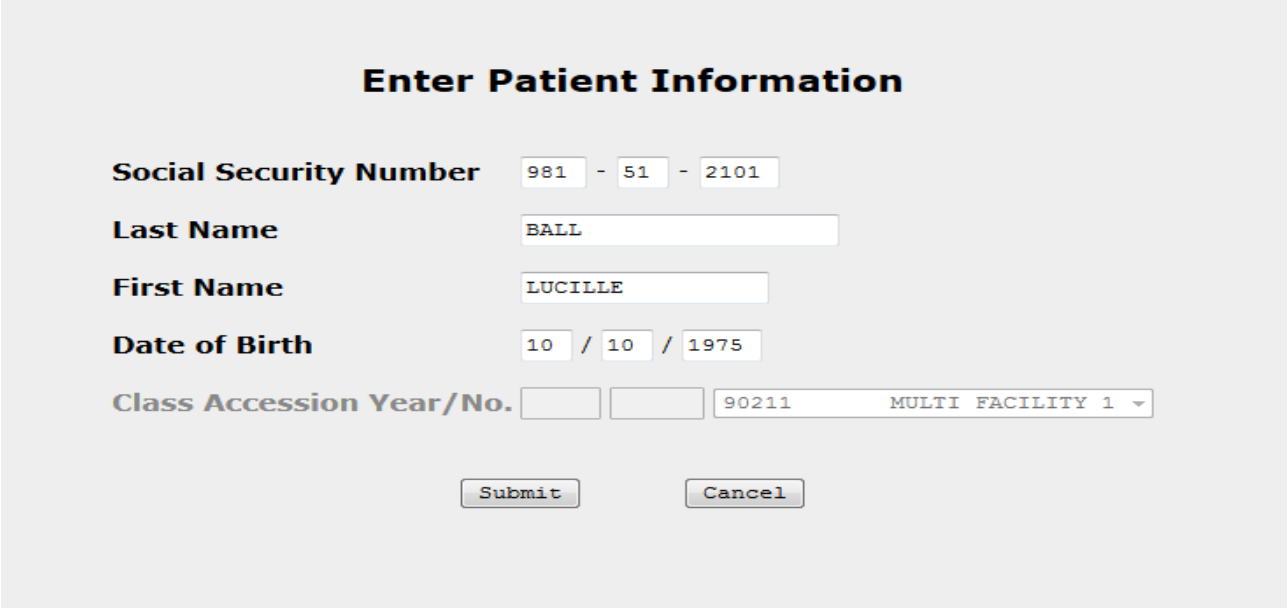
Objective

Review of coding guidelines and instructions to help give directions, clarity and understanding for the following:

- Social Security Number
- Last Name
- First Name
- Middle Names
- Surname (aka. Maiden Name)
- Address
- Race
- Ethnicity
- Clinical Trials

Social Security Number

- Recording the SSN accurately is essential
- Main element used in identifying patients & matching information (aka: consolidation)
  - Consolidation is done to ensure that all information about a patient's cancer(s) is in one central file

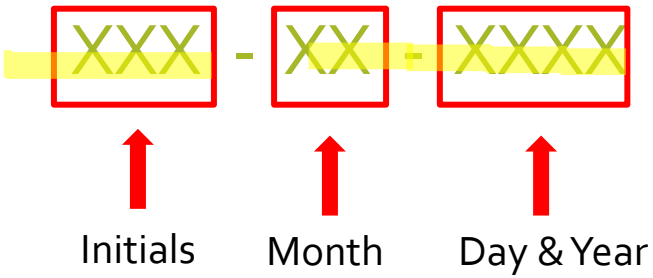


Missing SSN?

With the increase of data breaches and identity theft, some patients may opt to not list their social security numbers

If the patient doesn't have a Social Security Number on file, there is a formula for assigning a unique temporary number

- Use the initials of the patient's first, middle and last name followed by digits representing the 2-digit month, day and year of birth
- Use a **zero** when the middle initial is unknown



Examples:

Patient Name: Howard T. Duck
Date of Birth: August 1, 1986
SS#: Unknown

Formula SS#: HTD-08-0186

Patient Name: Roger Rabbit
Date of Birth: June 22, 1988
SS#: Unknown

Formula SS#: R0R-06-2288

What if you can't find a SSN for Lucille Esmerelda Ball born June 5, 1968

A. LEB- 05-0668

B. BLE-06-0568

C. LEB-06-0568

D. LoB-06-1968

E. Non of the above

What if your patient is Ethel Mertz (no middle name) born December 8, 1963?

A. E0M-12-0863

B. E0M-12-1963

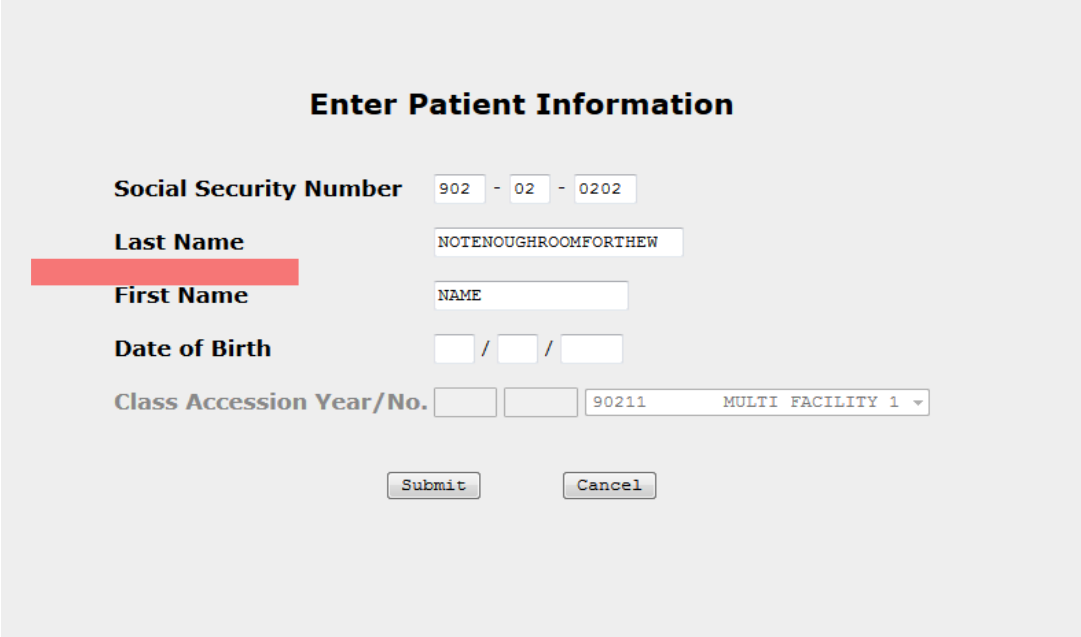
C. 0EM-12-0863

D. ME0-12-0863

E. None of the above

Last Name

- Enter the patient's last name in the space provided
- If the name exceeds the number of spaces, enter as much as possible
- *During follow-up, enter the new name if the patient's name has changed*



Last Name Rules

- ***Only*** alpha characters and blanks can be used
- Do ***not*** add name titles and suffixes (MD, Jr, Sr, II) in the last name field
- For matching, blanks ***must*** be used ***consistently***

  - When there are 2 last names (or a hyphenated name), you may type both separated by a blank space.
    - **Example:**

      Maye-Ramey, enter as Maye Ramey

  - Two-part last names may have a space, but no punctuation marks
    - **Examples:**

      Van Horn, enter as Van Horn

      St. John, enter as St John

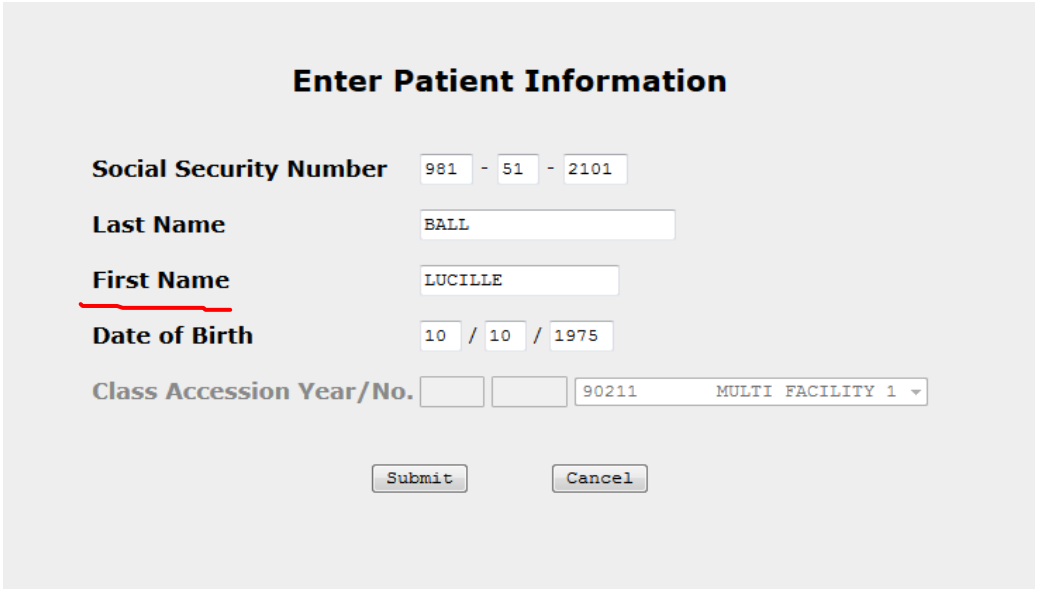
  - Names with prefixes like Mc or O' should be typed with no spaces or punctuation
    - **Examples:**

      McCoy, enter as McCoy

      O'Brian, enter as OBrian

First Name

- Enter the patient's first name in the space provided
- If the name exceeds the number of spaces, enter as much as possible



First Name Rules

Same as last name rules with a few key differences

- When there is a 2 part first name (or 2 first names) both may be recorded separated by a blank space
  - **Example:**

    Jo Ann, type as Jo Ann
- Patients who go by their initials should have the first initial in the first name field and the second in the middle name field
  - **Example:**

    JT, Type as J (First name field) and T (Middle name field)
- Patients with an initial and a name should have them recorded in separate fields also
  - **Example:**

    D Angelo, type as D (First name field) and Angelo (Middle name field)

Middle, Maiden & Surnames

- See the rules for first and last names
- Titles or suffixes are optional and can be recorded in the middle name field

  Important: Though the suffix or titles usually falls after the last name, they DO NOT go in the last name field.

- Maiden and Surnames are required fields if they are available
  - Leave maiden and surnames blank for males

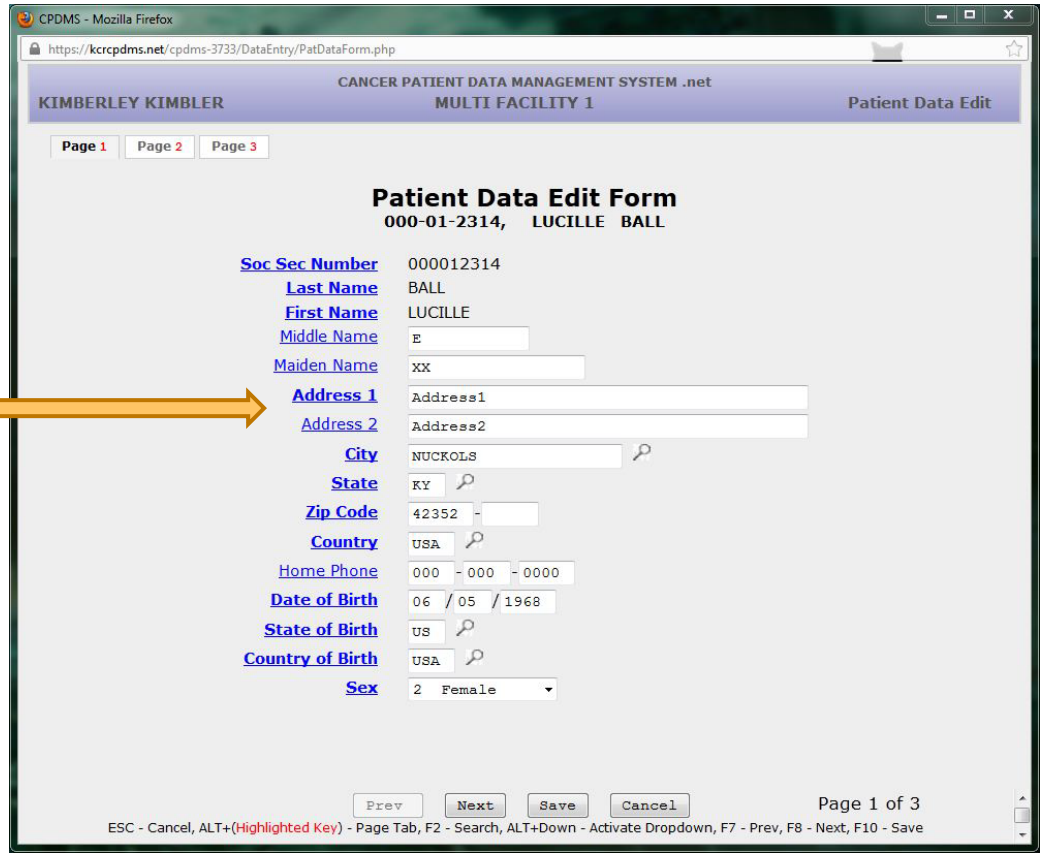
    or
  - Leave blank if they are unknown

Patient Address

See those **blue** links?

They take you to useful information!

When they are **BOLD**, this tells you that the field is required



Race

- Race and ethnicity are defined by specific physical, hereditary and cultural traditions or origins, not necessarily by birthplace, place of residence, or citizenship.
- ‘Origin’ is defined by the U.S. 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.
- The five race data items (Race 1 – Race 5) make it possible to code multiple races for one person, consistent with the 2000 Census.
- All resources in the facility must be used to determine race.
  - Medical Record
  - Face Sheet
  - Physician Notes
  - Nursing Notes
  - Photographs
  - any Other Sources

Priorities for Coding Multiple Races

Code 07 (Hawaiian) takes priority over all other codes

Example: Patient is described as Japanese and Hawaiian. Code Race 1 as 07 (Hawaiian), Race 2 as 05 (Japanese)

Important: Living or having lived in Hawaii does not always equate Hawaiian

Code Hawaiian when:

- Patient is described as Hawaiian
- Patient has Hawaiian surname and originated from Hawaii
- Patient states that one or both parent are Hawaiian

- Codes 02-32, 96-98 take priority over code 01 (White)
- Code only the specific race when both a specific race code and a non-specific race code apply
- Codes 04-17 take priority over code 96
- Codes 16-17 take priority over code 15
- Codes 20-32 take priority over code 97
- Codes 02-32 and 96-97 take priority over code 98
- Code 98 takes priority over code 99

Coding Rules and Guidelines

Self-reported race information is the gold standard!

- Self-reported information is the highest priority for coding race because the race information for the U.S. population comes from census data and that information is self-reported.
  - For national cancer statistics, in order for the number of cancer cases and the population to be comparable, use self-reported race information whenever it is available.
- Self-reported race information takes precedence over genetic testing and over information obtained through linkages.
  - Race information is used from linkages when race data are missing or unknown, or to enhance data.

What to do when there is conflicting information

Code race using the highest priority source available when race is reported differently by two or more sources. ***Use self-reported information as first priority.***

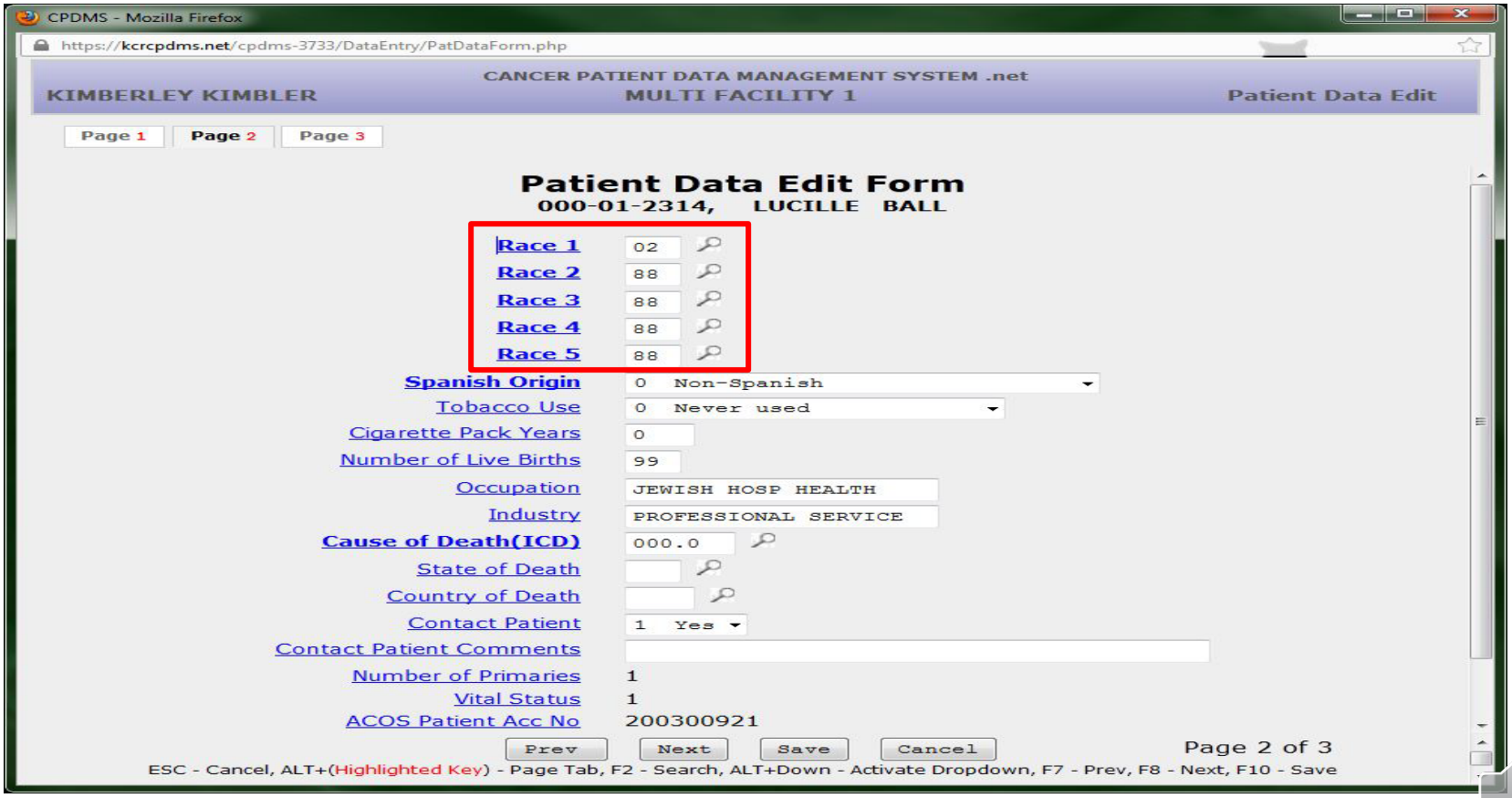
- The patient's self-declared identification
- Documentation in the medical record
- Death certificate

Be Consistent!

- Assign the same race code(s) for ***all*** tumors for one patient (cannot be one race for one cancer and another race for another).

Code the race(s) of the patient in data items Race 1, Race 2, Race 3, Race 4, and Race 5

Code 88 for the remaining race data items (Race 2 – Race 5), when fewer than five races, are reported



- **Cover your abstracting!**

  Use the associated text field to document why a particular race code was chosen when:

  - There are discrepancies in race information

    Example: The patient is identified as Black in nursing notes and White in a dictated physical exam.

  - There is no race information is available

When to code 01 (White)

- The race is described as White or Caucasian ***regardless*** of place of birth

- There is a statement that the patient is Hispanic or Latino(a) and no further information is available
  - Persons of Spanish or Hispanic origin may be of ***any*** race, although persons of Mexican, Central American, South American, Puerto Rican, or Cuban origin are usually White.
  - Coding race when there is no further information other than "Hispanic" or "Latino(a)," assign race 01 White as a last resort instead of coding unknown.
  - Do not code 98 (Other) in this situation.

    Example: Sabrina Fitzsimmons is a Latina. No further information is available. Code race as 01 (White).

Remember: Hispanic and Latino are ***Ethnicities***

When to code 02 (Black)

- Code race as 02 (Black) when race is stated as:
  - African-American
  - Black
  - Negro

When to code 03 (American Indian, Aleutian, or Alaska Native (includes all indigenous populations of the western hemisphere))

- Assign code 03 for any person stated to be:
  - Native American (western hemisphere)
  - Indian, whether from North, Central, South, or Latin America

Coding an Asian Race

- Assign a specific code when a specific Asian race is stated
  - Do ***not*** use code 96 when a specific race is known
    - **Example**: Patient is described as Asian in a consult note and as second generation Korean-American in the history. Code Race 1 as 08 (Korean) and Race 2 through Race 5 as 88

- Do ***not*** code 96 (Other Asian including Asian, NOS and Oriental, NOS) in a subsequent race data item when a specific Asian race has been coded

- Code the race based on birthplace information when the race is recorded as Oriental, Mongolian, or Asian and the place of birth is recorded as China, Japan, the Philippines, or another Asian nation

  Example 1: Race is recorded as Asian and the place of birth is recorded as Japan. Code race as 05 (Japanese) because it is more specific than 96.

  Example 2: The person describes himself as an Asian-American born in Laos. Code race as 11(Laotian) because it is more specific than 96.

- Use the appropriate non-specific code 96 (Other Asian including Asian, NOS and Oriental, NOS), 97 (Pacific Islander, NOS), or 98 (Other) when there is no race code for a specific race

Remember: Document the specified race in a text field

Last Resort Codes (96, 97, 98, 99)

- All other codes are to be used over these
- Follow the rules and examples when coding “multi-racial”
  - Do not use code 96, 97, or 98 for “multi-racial.”
- All race data items must be coded 99 (Unknown) when Race 1 is coded 99 (Unknown)
  - Note: Assign code 99 in Race 2-5 only when Race 1 is coded 99
- Assign code 99 for death certificate only (DCO) cases when race is unknown

Appendix D

- Lists are in numerical order as well as alphabetical
- Refer to Appendix D “Race and Nationality Descriptions from the 2000 Census and Bureau of Vital Statistics” when race is unknown or not stated in the medical record and birthplace is recorded
- In *some* cases, race may be inferred from the nationality. Use Appendix D to identify nationalities from which race codes may be inferred.

  Example 1: Record states: “this native of Portugal...” Code race as 01 (White) per the Appendix

  Example 2: Record states: “this patient was Nigerian...” Code race as 02 (Black) per the Appendix

- **Exception:** Code Race 1 through Race 5 as 99 (Unknown) when patient’s name is not consistent with the race inferred on the basis of nationality. Do not code the inferred race when the patient’s name is inconsistent with the race inferred on the basis of nationality.

  Example 1: Patient’s name is Nina Rao and birthplace is listed as England. Code Race 1 through Race 5 as 99 (Unknown)

  Example 2: Patient’s name is Ping Chen and birthplace is Ethiopia. Code Race 1 through Race 5 as 99 (Unknown)

Appendix also contains additional coding guidance and rules

Note 1: The following descriptions of ethnic origin cannot be coded to a specific race code.

- Aruba Islander
- Azerbaijani
- Belizean
- Bermudan
- Cayenne Cayman
- Islander Guyanese
- Indian (not specified as Native American, Eastern Indian, Northern, Central, or South American Indian)
- Mestizo
- Morena
- South African Surinam
- Tejan

If race is listed as one of the above descriptions:

- Look for other descriptions of race in the medical record
- If no further information is available, code as 99 Unknown

Note 2: The following terms self-reported in the 2000 Census cannot be coded to a specific race code

- Biracial
- Interracial Mixed
- Multiethnic
- Multinational
- Multiracial

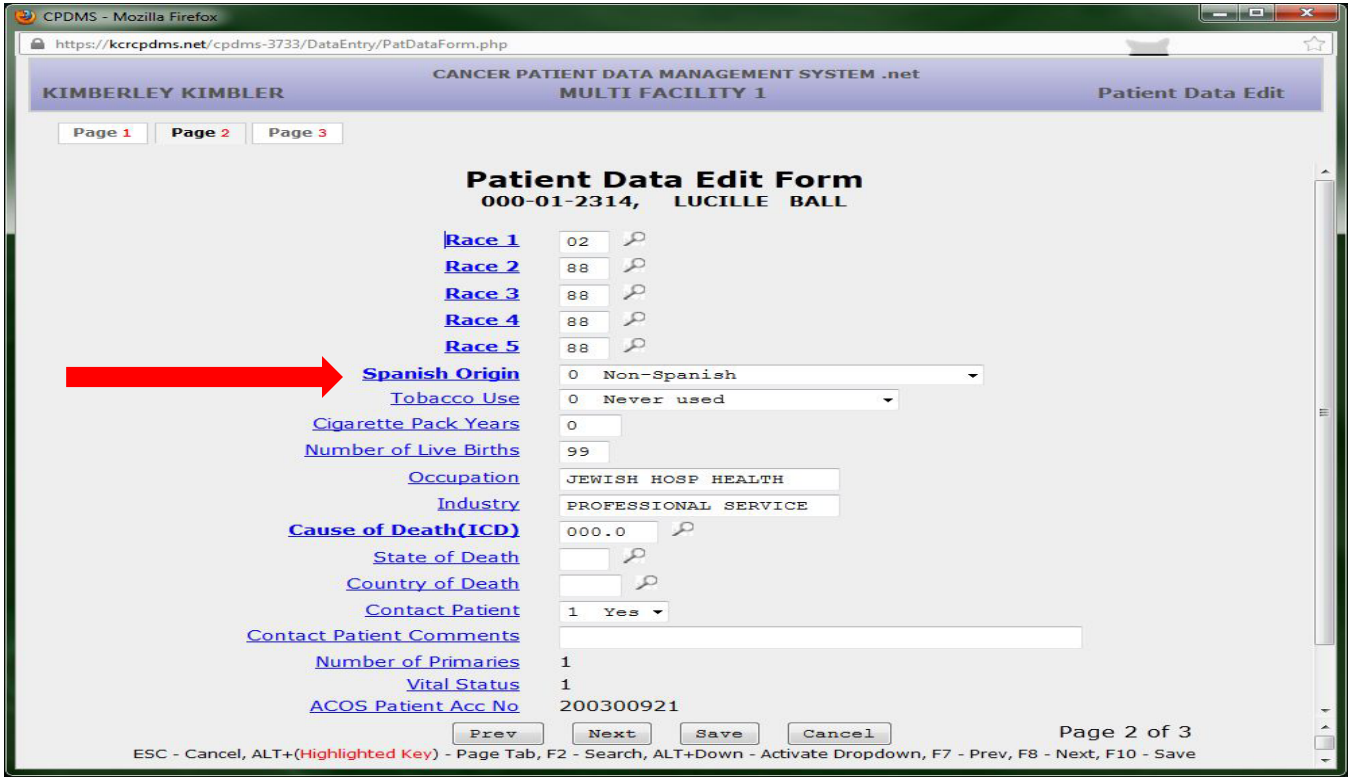
If race is listed as one of the above descriptions:

- Look for other descriptions of race in the medical record
- Follow the coding rules of priority race coding
- When stated as more than one race, 01 (white) is coded last

  Example: Patient listed as multiracial, father is white and mother is African-American. Race 1: (02) Black, Race 2: (01) White

- If no further information is available, code as 99 Unknown

Spanish Origin: Race vs. Ethnicity



Race: A human population considered distinct based on ***physical*** characteristics

Ethnicity: A term which represents social groups with a shared history, sense of identity, geography and ***cultural*** roots which may occur despite racial difference

Spanish Origin

NAACCR Item #: 190
SEER Manual: Pages 73-74

Code	Description
0	Non-Spanish/Non-Hispanic
1	Mexican (includes Chicano)
2	Puerto Rican
3	Cuban
4	South or Central American (except Brazil)
5	Other specified Spanish/Hispanic origin (includes European; excludes Dominican Republic)
6	Spanish, NOS; Hispanic, NOS; Latino, NOS There is evidence, **other than surname or maiden name**, that the person is Hispanic but he/she cannot be assigned to any of the categories 1-5.
7	Spanish surname only (effective with diagnosis on or after 01/01/1994) The **only** evidence of the person's Hispanic origin is the **surname or maiden name (birth surname)** and there is **no evidence that he/she is not Hispanic.**
8	Dominican Republic (effective with diagnosis on or after 01/01/2005)
9	Unknown whether Spanish/Hispanic or not

- 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
- Coding Spanish Surname or Origin is not dependent on race
  - A person of Spanish descent maybe white, black, or any other race
- Use all information to determine the Spanish/Hispanic Origin including:
  - The ethnicity stated in the medical record
    - Self-reported information takes priority over other sources of information
  - Hispanic origin stated on the death certificate
  - Birthplace
  - Information about life history and/or language spoken found in the abstracting process
  - A last name or maiden name (birth surname) found on a list of Hispanic/Spanish names

- There is no hierarchy among the codes 1-5 or 8.
- Assign code 6 when there is more than one ethnicity/origin (multiple codes), such as Mexican (code 1) and Dominican Republic (code 8).
- Assign code 7 when the only evidence of the patient's Hispanic origin is a surname or maiden name (birth surname) and there is no evidence that the patient is not Hispanic.
  - Code 7 is ordinarily for central registry use only
- Assign code 9 for death certificate only (DCO) cases when Spanish/Hispanic origin is unknown

Portuguese, Brazilians, and Filipinos

Portuguese, Brazilians, and Filipinos are ***not*** presumed to be Spanish or non-Spanish

Filipinos can be Hispanic? Yep

Spanish Philippines is the history of the Philippines from 1521 to 1898. The Spanish conquest of 1565, prompted the colonization of the Philippine Islands making the Philippines an overseas province of Spain. Spain's rule over the Philippines ended with the outbreak of the Spanish-American War in 1898.

Portugal and Brazil speak Portuguese "Hispanic" accentuates the Spanish language and though Brazil is located in Central America, Brazilians are no "Hispanic".

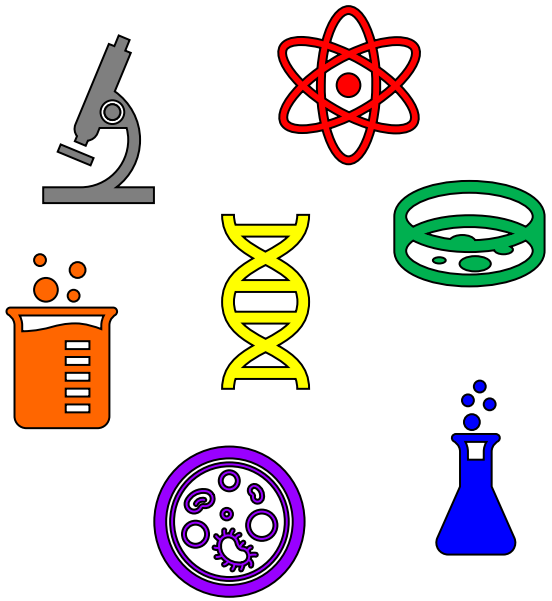
- Assign code 7 when the patient is Portuguese, Brazilian, or Filipino ***and*** their surname or maiden name ***appears*** on a Hispanic surname list

- Assign code 0 when the patient is Portuguese, Brazilian, or Filipino ***and*** their surname or maiden name does ***NOT*** appear on a Hispanic surname list

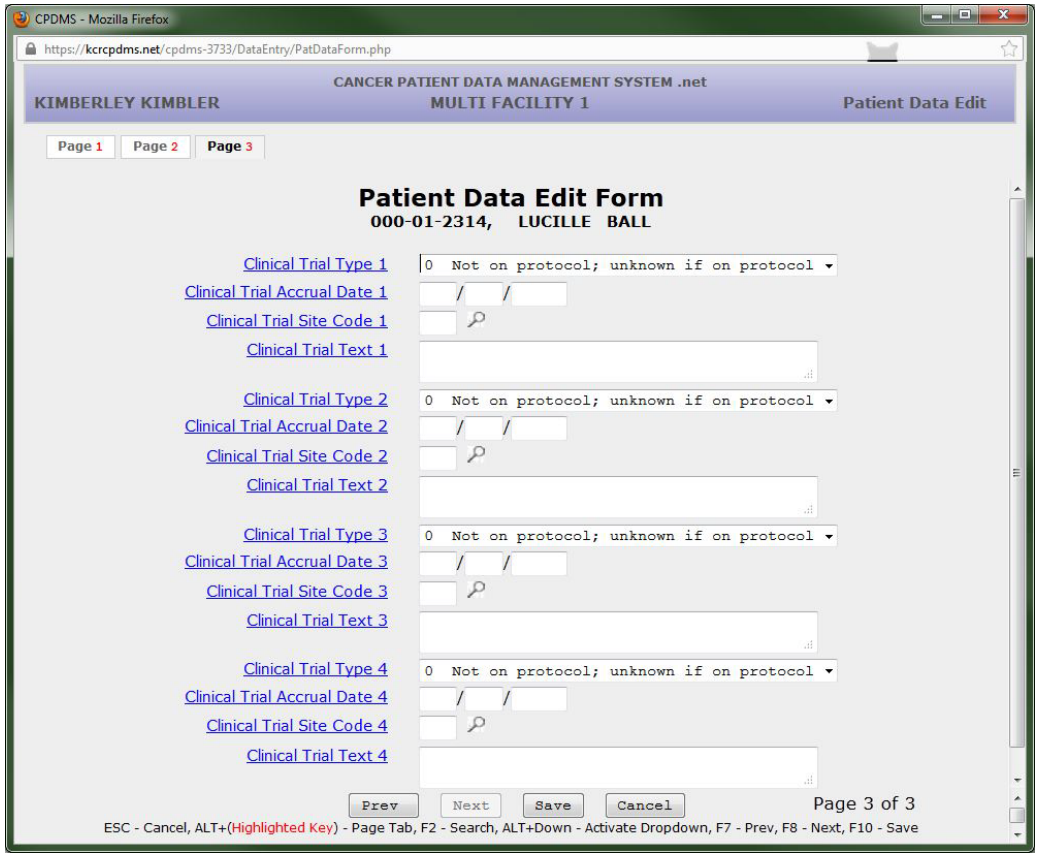
- Hispanic refers to individuals who are Spanish-speaking or have a background in a Spanish-speaking country. Latino refers to those who are from or have a background in a Latin American country.
- If patient is referred as ”latino(a)”, check for additional information that states origin.
  - If additional information states origin as Hispanic, assign proper code (1-5)
  - If there is evidence, other than surname or maiden name, that the person is Hispanic, but he/she ***cannot*** be assigned to any of the categories 1-5, Code 6 (Spanish, NOS; Hispanic, NOS; Latino, NOS)
  - If additional information states patient is Portuguese, Brazilian or Filipino, and surname is on the “Hispanic Surname list”, code 7(Spanish surname only)
  - If additional information states patient is Portuguese, Brazilian or Filipino, and surname is ***NOT*** on the “Hispanic Surname list”, code 0 (Non-Hispanic, Non-Spanish)

Clinical Trials

- Fields added to capture patient participation in clinical trials at your institution
- Information can be added for up to 4 separate trials
- Free text field allows you to enter relevant information such as:
  - Trial number
  - Sponsor
  - Design
  - Protocol arm
  - Completion date



Clinical Trials



Resources

SEER Manual

https://seer.cancer.gov/manuals/2022/SPCSM_2022_MainDoc.pdf

SEER Manual Appendix D

https://seer.cancer.gov/manuals/2022/SPCSM_2022_Appendix_D.pdf

Hispanic Surname List

Manual does not give list or reference for list.

https://fcds.med.miami.edu/downloads/DataAcquisitionManual/dam2022/26%20Appendix%20E%20Census%20List%20of%20Spanish%20Surnames.pdf

True or False

1) If the patient's race is a combination of white and any other race(s), code the appropriate other race(s) first and then code white in the next field?
2) Race can be coded based solely on a patient's name?
3) Race can be coded as "Multiracial" only?
4) Race and Ethnicity are the same thing?
5) Patients described as "Cuban" are coded 01 (white)?
6) Patients described as "American" are always coded 01 (white)?
7) Office note describes patient as "biracial" but patient sel-report states white. Code patient's race as 98 (Other)?

True or False

1) If the patient's race is a combination of white and any other race(s), code the appropriate other race(s) first and then code white in the next field? **TRUE**
2) Race can be coded based solely on a patient's name? **TRUE**
3) Race can be coded as "Multiracial" only? **FALSE, there is no Code for "Multiracial"**
4) Race and Ethnicity are the same thing? **FALSE**
5) Patients described as "Cuban" are coded 01 (white)? **TRUE**
6) Patients described as "American" are always coded 01 (white)? **FALSE, American is nationality**
7) Office note describes patient as "biracial" but patient self-report states white. Code patient's race as 98 (Other)? **FALSE Code 01 (White)**

True or False

1) Patient was born in Kentucky and race coded 01 (white). Patient's last name is Ramirez and states that parents are originally from Mexico. Spanish Origin would be coded 0 (Non-Hispanic, Non-Spanish because patient was born in the U.S.?
2) Patient was born in Spain during father's military service. Patient's race coded 01 (White). Patient's last name is not on Hispanic surname list and states that parents are Non-Hispanic. Due to patient being born in Spain, Spanish Origin would be coded 5 (Other specified Spanish/Hispanic origin)?
3) Married female patient with race of 02 (Black), born in Ohio and maiden or birth surname is Wilson . Married surname is on Hispanic Surname List, patient lived in Mexico for 10 years and Spanish is the primary language spoken in the household. Spanish Origin would be coded 7 (Hispanic Surname only)?
4) Patients described as "Cuban-American" coded 03 (Cuban)?
5) Patients described as 02 (black) and born in New York to parents of Dominican decent. Spanish Origin coded 08 (Dominican Republic)?
6) Married female patient within unknown maiden/birth surname. Patient list race as 01 (white), place of birth is Brazil and states that she is "Non-Hispanic". Spanish Origin is coded 0 (Non-Hispanic, Non-Spanish)?
7) Patient was adopted and was "told" her birth mother was Hispanic and birth father was white. Patient stated her race as (unknown) but stated she was of Hispanic origin. Spanish-origin coded 09 (Unknown)?

True or False

1) Patient was born in Kentucky and race coded 01 (white). Patient's last name is Ramirez and states that parents are originally from Mexico. Spanish Origin would be coded 0 (Non-Hispanic, Non-Spanish because patient was born in the U.S.? **FALSE, code 1 (Mexican)**
2) Patient was born in Spain during father's military service. Patient's race coded 01 (White). Patient's last name is not on Hispanic surname list and states that parents are Non-Hispanic. Due to patient being born in Spain, Spanish Origin would be coded 5 (Other specified Spanish/Hispanic origin)? **FALSE, code 0 (Non-Spanish)**
3) Married female patient with race of 02 (Black), born in Ohio and maiden or birth surname is Wilson. Married surname is on Hispanic Surname List, patient lived in Mexico for 10 years and Spanish is the primary language spoken in the household. Spanish Origin would be coded 7 (Hispanic Surname only)? **FALSE, code 0 (Non-Spanish)**
4) Patients described as "Cuban-American" coded 3 (Cuban)? **TRUE**
5) Patients described as 02 (black) and born in New York to parents of Dominican decent. Spanish Origin coded 8 (Dominican Republic)? **TRUE**
6) Married female patient within unknown maiden/birth surname. Patient list race as 01 (white), place of birth is Brazil and states that she is "Non-Hispanic". Spanish Origin is coded 0 (Non-Hispanic, Non-Spanish)? **TRUE**
7) Patient was adopted and was "told" her birth mother was latino and birth father was white. Patient stated her race as (unknown) but stated she was of Hispanic origin. Spanish-origin coded 09 (Unknown)? **FALSE, Code 6 (Spanish, NOS, Hispanic NOS, Latino NOS)**

Any Questions?