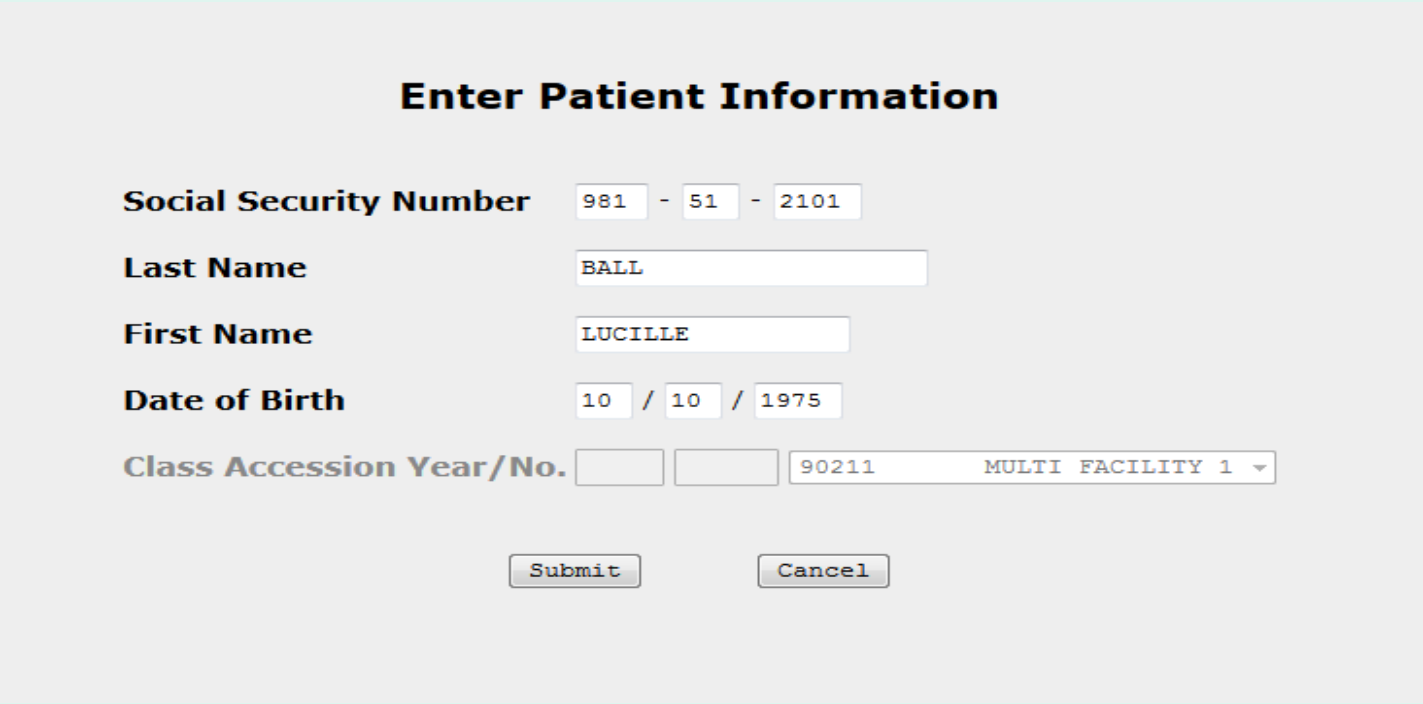
Patient Level Data

Social Security Number



- Main element used in identifying patients & matching information
- Recording the SSN accurately is essential

How to fake it…….

- If the patient doesn't have a verifiable SSN, 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

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

A. LEB-68-0605

B. BLE-06-0568

C. LEB-06-0568

D. L0B-05-0668

E. None of the above

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

A. E0M-12-0863

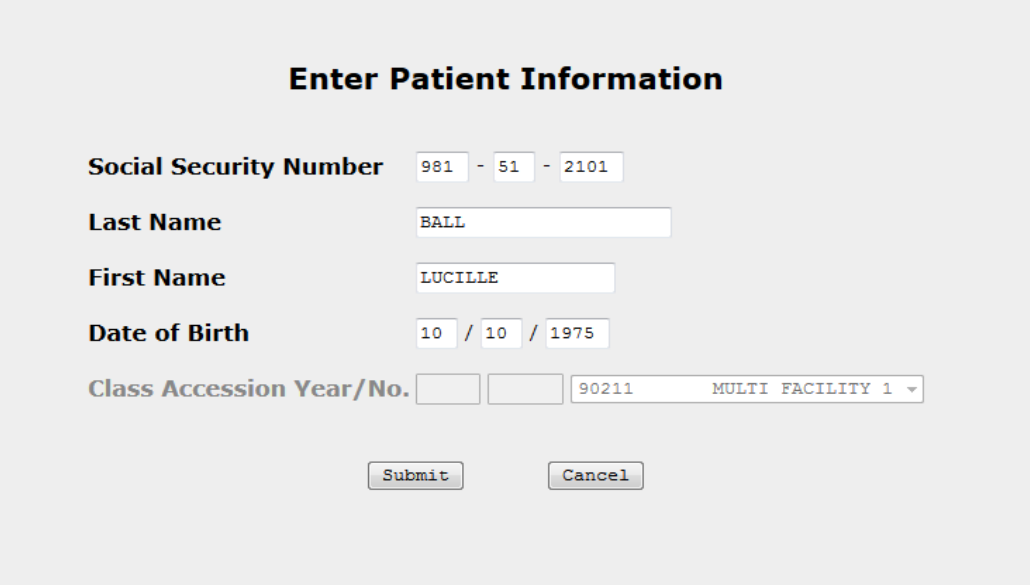
B. E0M-12-1963

C. 0EM-12-1963

D. 0ME-12-0863

E. None of the above

Last Name

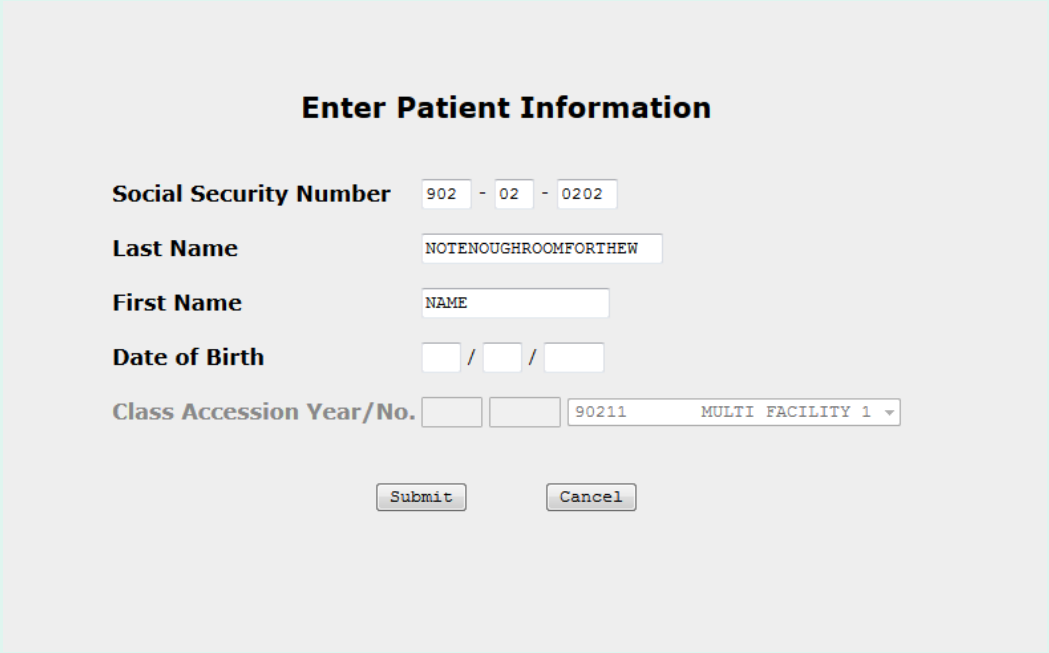


- Enter the patient's last name in the space provided
- If the name exceeds the number of spaces, enter as much as possible
- *During follow-up, enter the new name if the patient's name has changed*

Last Name Rules

- Only alpha characters and blanks
- Name titles and suffixes (MD, Jr, Sr, II) are optional, but they can be coded in the middle 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
  - Two part last names, like Van Horn or St. John, may have a space, but no punctuation marks
  - Names like McCoy or O'Bryan should be typed "MCCOY" and "OBRYAN" with no spaces or punctuation

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

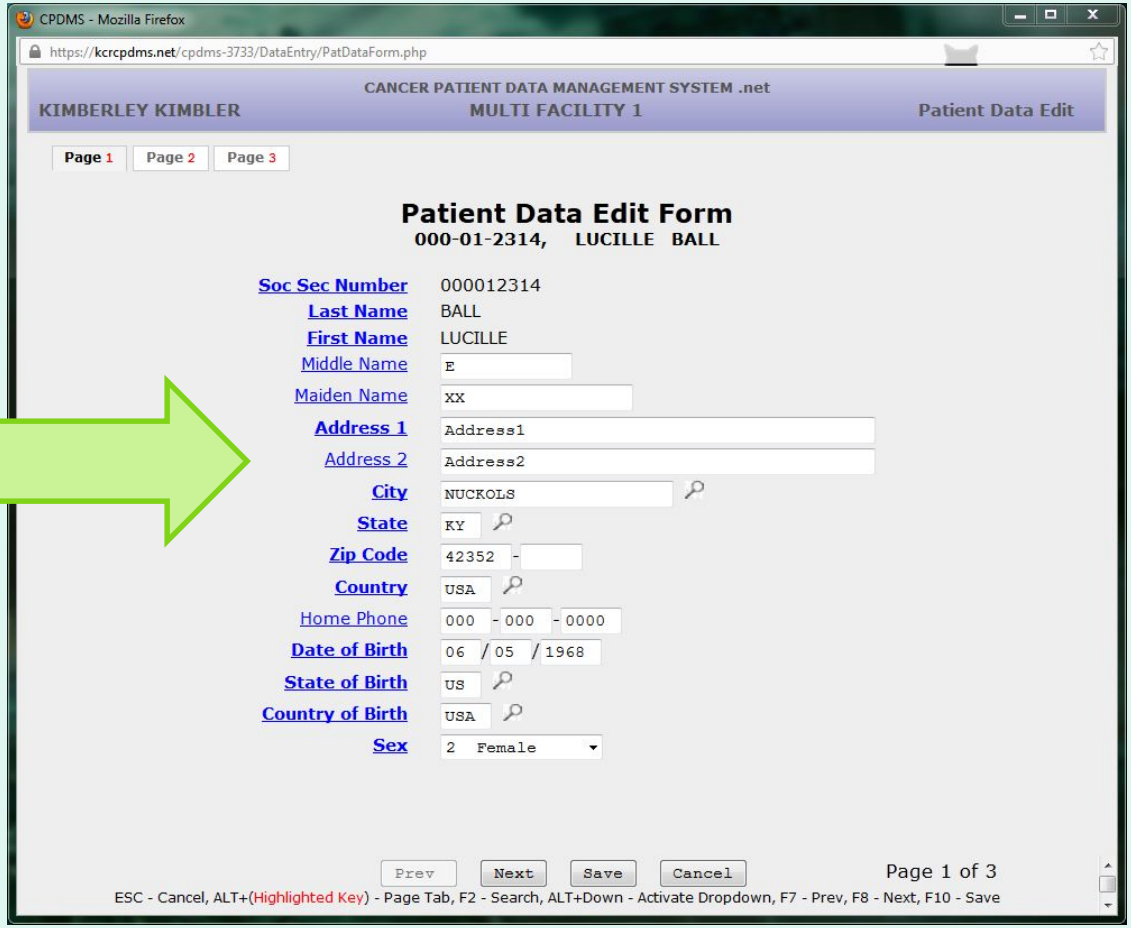
- Same as last name rules with a few key differences
  - When there is a 2 part first name (or 2 first names) both may be recorded separated by a blank space
  - Patients who go by their initials should have the first initial in the first name field and the second in the middle name field
  - Patients with an initial and a name should have them recorded in separate fields also

Middle & Maiden Names

- See the rules for first and last names
- Titles or suffixes can be recorded in the middle name field
- Maiden name is a required field if it is available
  - Leave maiden name blank for males or if it is unknown

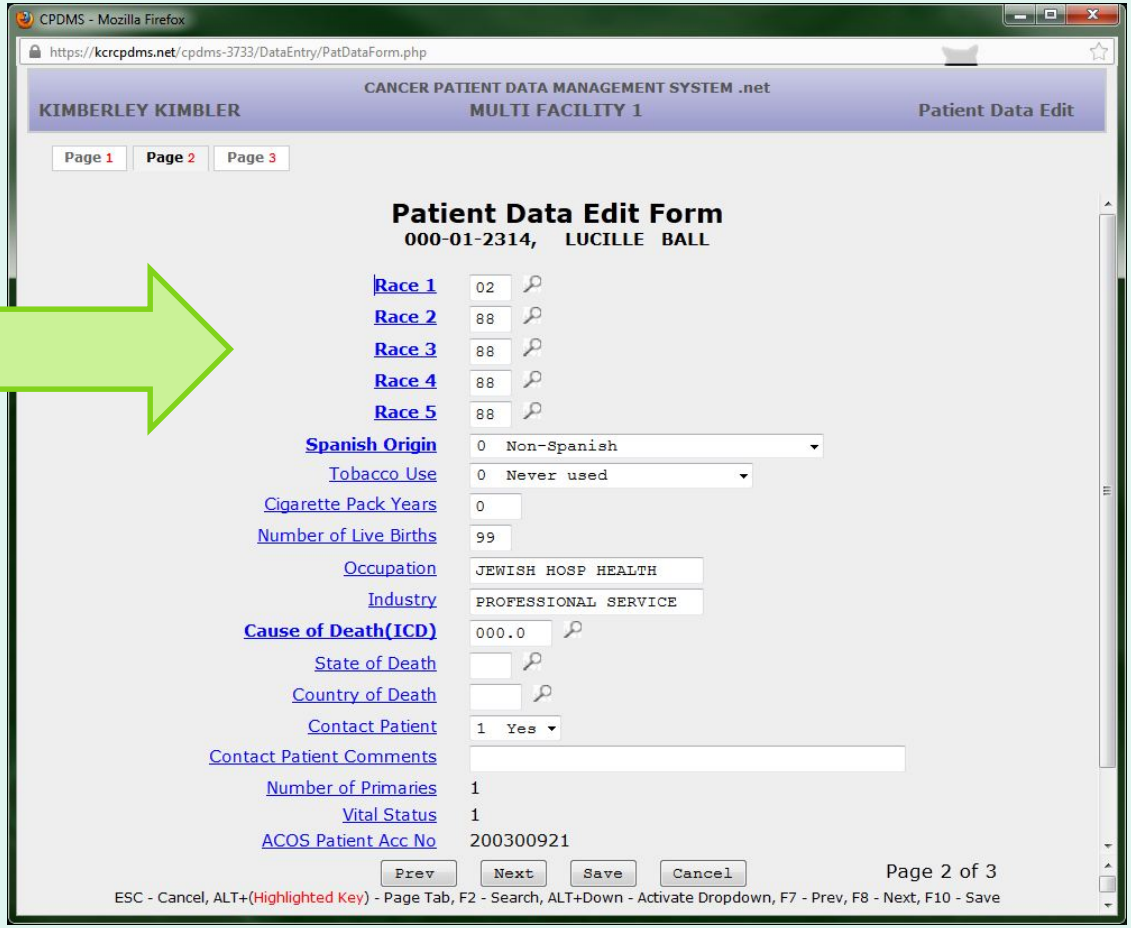
Patient Address

See those blue links? They take you to useful information



Race: It's Really Important!

Race is critical information! Please avoid coding race as "unknown" (aka 99) or "other race" (aka 98) if at all possible.

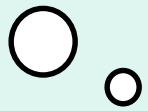


More rules ahead……

- The rules for coding race can be found at …..
- https://confluence.kcr.uky.edu/display/KAM/Appendix+K+-++Race+Coding+Rules+and+Tables
- More info and examples can also be found in the SEER coding manual at …..

http://seer.cancer.gov/tools/codingmanuals/

https://seer.cancer.gov/archive/manuals/2016/SPCSM_2016_AppendixD.pdf



Race Rules

- *If a patient's race is a combination of white and any other race(s), code the other race(s) first and code white in the next race field.*

- Code the patient's stated race if possible.

- Use the most specific code if you can justify doing so (e.g. 05 Japanese vs 96 Asian where record states born in Japan).

Race Rules

- In some cases, race can be inferred from place of birth (nationality), but not always…
- Persons of Spanish or Hispanic origin may be of any race, but those from Mexico, Central/South America, Puerto Rico or Cuba are usually white.
- *Do not code race from name alone!*

TRUE or FALSE?

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 or FALSE?

Race can be coded based solely on a patient's name.

A pediatric patient is described as multi-racial. Notes state that one of her parents is Caucasian and the other is African American. Race should be coded..

Race 1: 02 (black), Race 2: 01 (white), Race 3-5: 88.

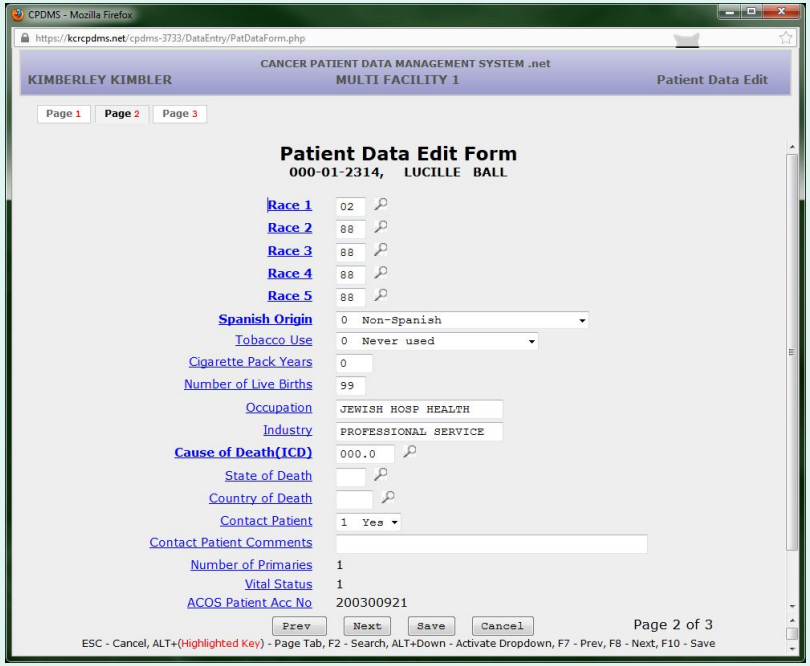
If a person is multi-racial and one of the races is white, code the other race(s) first with white in the next race field .

What if there's conflicting information regarding race (e.g. patient is identified as black in nursing notes and white in physical exam note)?

Use your best judgment and all of the information available to try to determine the correct code

Use the text field to document and justify the code(s) used

Spanish Origin: Race vs. Ethnicity



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

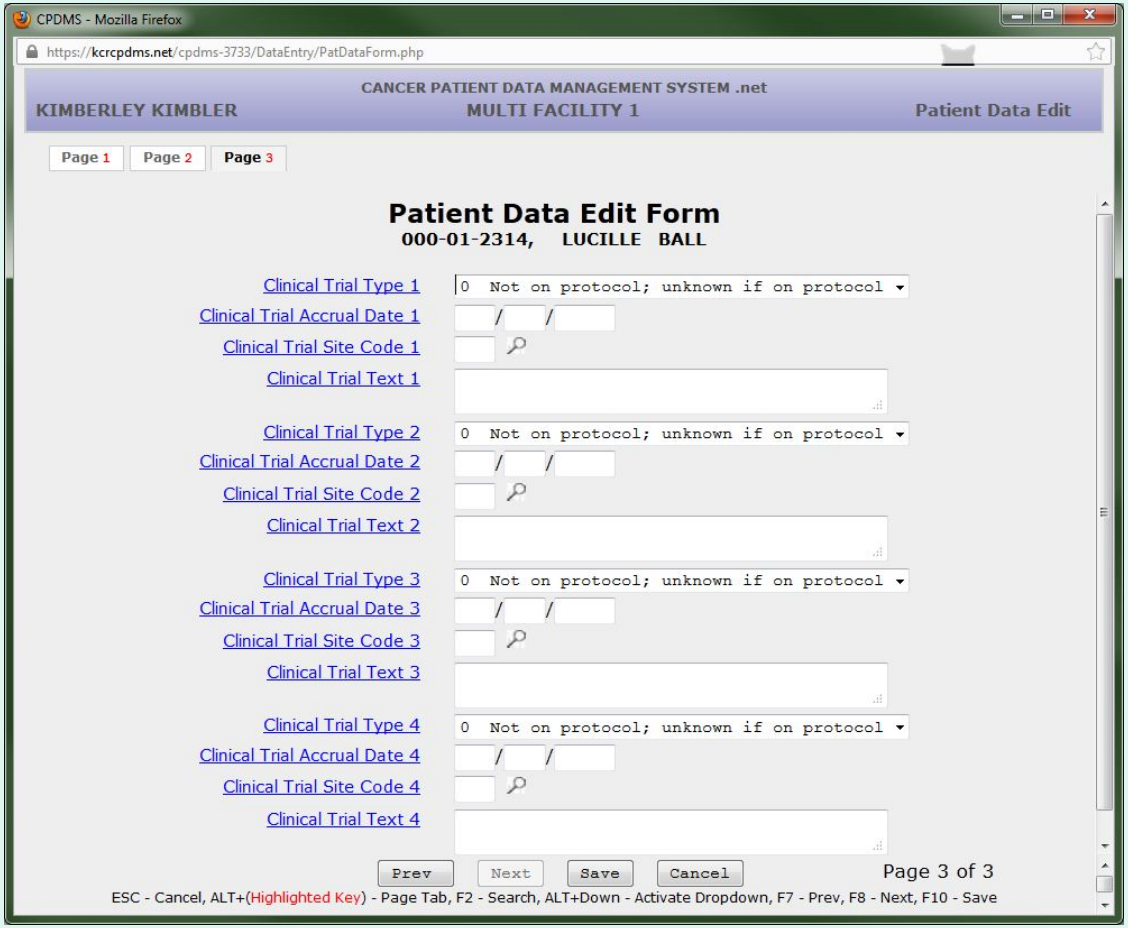
Ethnicity: A term which represents social groups with a shared history, sense of identity, geography and **cultural** roots which may occur despite racial difference.

Hispanic or Latino - A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race.

Clinical Trials

- New 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



Any questions?