

Recording Demographics in Clinical Research

Clinical research results are more accurate when diverse populations are represented. It is vital to explain both how a study was done, and who was being studied. Researchers who receive NIH funding have been required, since 1993, to report race, ethnicity, and gender of participants in their biomedical research. Many different databases collect a single participant's demographics but study teams should ensure they specifically ask study participants about how they identify with regard to their race, ethnicity, and gender.

Asking a Person for their Demographics:

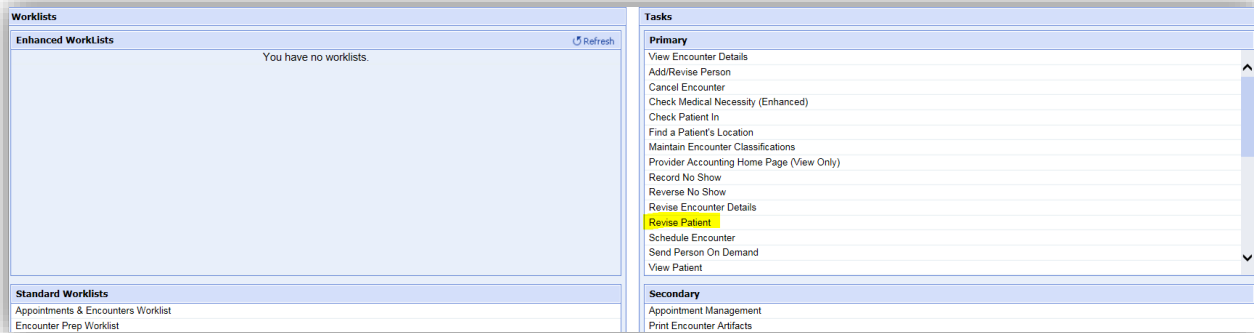
- **Race:** Ask the participant how they identify. Some participants identify as more than one race. This may not be an option in medical systems. In this case, ask their preference and record this information. Never assume a person's race by looking at them, you must always ask!
 - Encourage the participant by stating diversity in clinical research is important to us, we want to make sure we accurately confirm this information so we have accurate data from the research with regard to every participant's demographic information. Racial and ethnic minorities have more preventable diseases and poorer health outcomes (i.e., health disparities), but are not reflected in research studies as much as the racial and ethnic majority.
 - **Examples of Race:**
 - White or Caucasian - British, French, German, etc.
 - African American or Black - Kenyan, Nigerian, Somalian, biracial, etc.
 - American Indian or Alaska Native - Iroquois, Cherokee, Navajo, Haida, etc.
 - Latino or Hispanic - Cuban, Mexican, Puerto Rican, etc.
 - Asian - Japanese, Korean, Chinese, Cambodian, etc.
 - Pacific Islander or Hawaiian - Samoan, Tongan, Maori, Tahitian, etc.
- **Ethnicity:** refers to shared cultural characteristics such as language, ancestry, practices, and beliefs. Hispanic ethnicity refers to persons of Cuban, Mexican, Puerto Rican, or other Spanish cultures or origins regardless of race. Be mindful when asking the participant's ethnicity.
 - **Examples of Ethnicity:**

▪ Hispanic or Latino	▪ Arab
▪ Italian	▪ Caribbean
▪ Irish	▪ African
▪ Chinese	
- **Sex assigned at birth and gender:** When asking about sex and gender identity, keep in mind the following:
 - **Sex** assigned at birth is a category given to a person as defined by visible characteristics. The person's sex might differ from what you perceive when you look at them today, to the next visit, to another encounter with a different department. Do not be afraid to ask.
 - **For example:** You perceive the current participant be male, but they could identify as female.
 - **Gender** is fluid and describes how a person identifies. It may be different than the sex they were assigned at birth. Do not be afraid to ask.
 - **Example:** You perceive the current participant to be male, but they are currently identifying as nonbinary (i.e., not identifying as exclusively male or female).

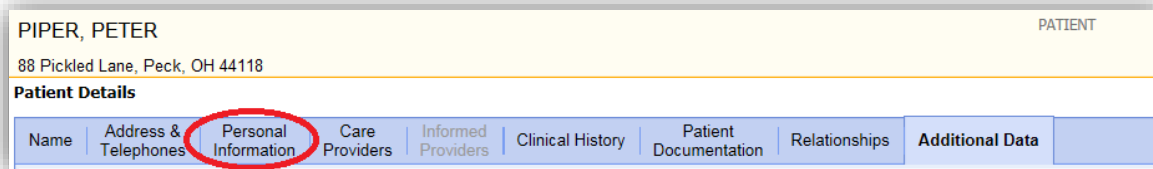
Confirming Demographics in Soarian:

When in Soarian, the study team should confirm the demographics match the demographics they captured during the study visit. This process needs to be accurate for billing.

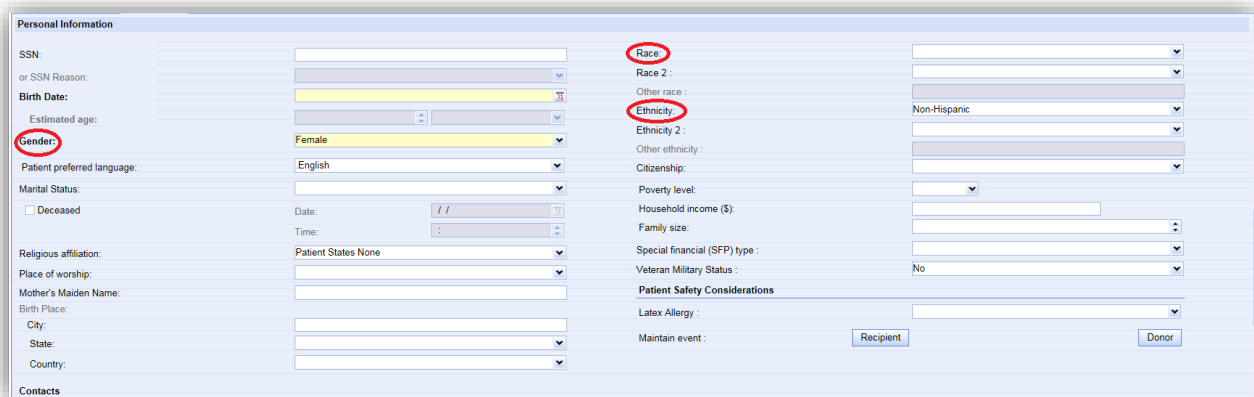
1. Log into Soarian
 - a. If you do not have access to Soarian, contact your manager and sign up for the training course.
2. Select **Revise Patient** from the main screen



3. Search for your participant of interest
4. Select the participant to open their Patient Details
5. Choose the **Personal Information** tab



6. This will show the patient's demographics. If there is a discrepancy, edit the demographics information

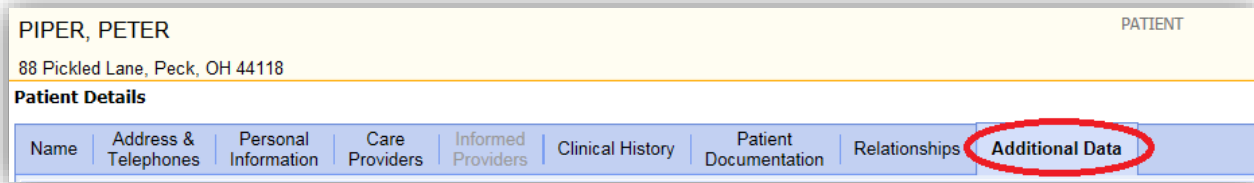


7. When done with participant's record, click **Done** in the bottom right corner

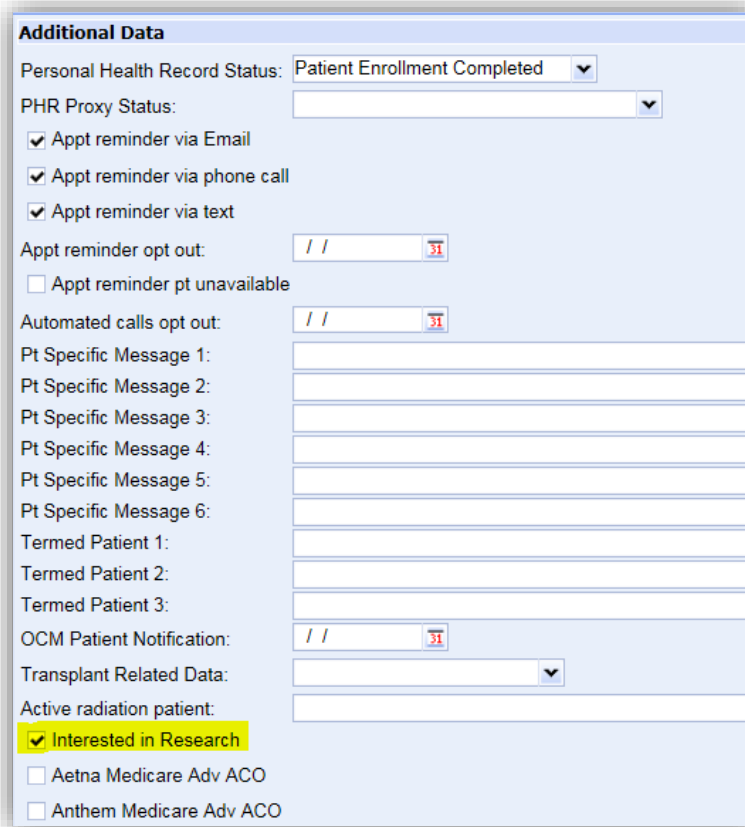
Recording Information for Clinical Research in Soarian:

There is an option within Soarian to select, **Interested in Research**. *This is different from billing for research and using research as the primary insurance.*

1. Log into Soarian
2. Select **Revise Patient** from the main screen
3. Search for the participant of interest
4. Select the participant to open their Patient Details
5. Once you open up the participant, select **Additional Data** from the tabbed menu



6. Scroll down to **Interested in Research** and select the box.



7. When done with participant's record, click **Done** in the bottom right corner.

For additional assistance, contact ClinicalResearch@UHhospitals.org | visit UHhospitals.org/Clinical-Research