1. \*Gender (Choose one):

Male

Female

Unknown

Unspecified

Not reported

1. \*Genotypic sex:

XX  XYY

XY  Unknown

XXX  Unspecified

XXY  Other, specify:

1. \*Date of birth
2. \*Ethnicity (“X” ONLY one with which you MOST CLOSELY identify):

Hispanic or Latino

Not Hispanic or Latino

Unknown

Not Reported

1. \*\*\*Ethnicity pertinent to intracranial aneurysm

Japanese  Arabic

Finnish  Southeast Asian

Eastern Asian  South Asian

European  Pacific Islander

Persian  American Indian

1. \*Race category (Choose all those with which you identify):

American Indian or Alaska Native

Asian

Black or African-American

Native Hawaiian or Other Pacific Islander

White

Unknown

Not reported

1. Race expanded category:

Black African American  Black African

Black Afro-Caribbean  South/Central American Indian

North American Indian  Alaskan Native

Inuit  South Asian

Far Eastern Asian  Western Asian

1. \*\*\*Country of residence:

USA (US)

Canada (CA)

United Kingdom (GB)

Mexico (MX)

Australia (AU)

China (CN)

India (IN)

Japan (JP)

Germany (DE)

France (FR)

Other European

Russia (RU)

Other Asian

Finland (FI)

Other, specify:

1. \*\*\*Country of residence name:
2. \*\*\*First 3 digits of zip code:
3. \*\*\*Social security number:

## General Instructions

This form contains data elements that are collected to describe the demographics of the study population. The items are used to compare baseline characteristics among study groups and to identify confounding variables.

* The NIH Guidelines on the Inclusion of Women and Minorities as Subjects in Clinical Research: The Office of Management and Budget Directive No. 15, defines the minimum standard of basic racial and ethnic categories. ([Click here for the NIH Guideline on the Inclusion of Women and Minorities](http://grants.nih.gov/grants/funding/women_min/guidelines_update.htm)) NIH has chosen to continue the use of these definitions because they allow comparisons across many national data bases, especially national health data bases. Therefore, the racial and ethnic categories included on the CRF should be used as basic guidance, cognizant of the distinction based on cultural heritage.

## Important Note: The data elements on this CRF Module are classified as supplemental (unless indicated by an asterisk below) and should only be collected if the research team considers them appropriate for their study. Please see the Data Dictionary for element classifications.

\*This element is classified as Core.

\*\*\*This element is classified as Exploratory.

## Specific Instructions

Please see the Data Dictionary for definitions for each of the data elements included in this CRF Module.

Responses to the demographic elements should be obtained from self-report when possible.

* Gender type – Self-reported gender of the participant/subject. Gender is the socially constructed identity of sex. Gender is equated with phenotypic sex. Gender may differ from the sex of an individual determined genetically. The NIH Guidelines on the Inclusion of Women and Minorities as Subjects in Clinical Research: The Office of Management and Budget Directive No. 15 ([Click here for the NIH Guideline on the Inclusion of Women and Minorities](http://grants.nih.gov/grants/funding/women_min/guidelines_update.htm))
  + Unspecified is defined as Undifferentiated/Indeterminant/Intersex
* Date of birth – Record the date of birth to the level of precision known (e.g., month/day/year, year, month/year, etc). The preferred format for recording date is MM/DD/YYYY. 99/99/9999 can be used to indicate an unknown date.
* Ethnicity – Choose only one with which the participant/subject most closely identifies.
* Country of residence –It may be easier to record the full name of the country and code the data later using the ISO 3166-1 alpha-2 codes.
* Race – Choose all that apply. Response is obtained by report of the participant/subject or caretaker. Collecting information on race may not be allowed in some countries for concerns related to discrimination. In other countries, however, these concerns are considered a reason for recording race in order to guarantee equal access to care. Investigators receiving funding from the US National Institutes of Health (NIH) are required to report the number of subjects enrolled on an annual basis using the racial categories listed.
* First 3 digits of zip code – This is an optional field, if this information is not provided enter 000.
* Social security number – Providing this information is entirely voluntary and the participant/ subject may refuse. This information must be kept confidential according to the Privacy Act of 1974, and must only be used for research purposes.