

Race

Ethnicity

Thinking Critically About Enrollment Data

Data Collection Method **Patient Level**

Self-report Of Race / Ethnicity

...is the gold standard.

Intake Based

...are less desirable and accurate methods.

- Surname
- Determined by staff (*patient appearance*)
- Primary language or need for interpreter
- Birthplace, citizen vs. non-citizen

Data Collection Method **Institutional Level**

For your institution, understand...

How is data collected?

Who collects and analyzes data?

How are data verified?

How often are data collected?

Understanding Race and Ethnicity

Race

Asian

Black

Hawaiian/
Pacific
Islander

Hawaiian/
Pacific
Islander

White

More than
one race

Unknown

Ethnicity

Hispanic/
Latino

Non-
Hispanic/
Latino

Limitations of Inclusion of Women and Minorities Form

- Category definitions are institute defined
- Includes both therapeutic and non-therapeutic trials
- Data are only as accurate as the original source
- Garbage in/Garbage out

Think Critically And Identify Potential Issues In Data Collection

- How is each category defined?
- What subjects are excluded?
- How are multi-racial subjects categorized?

Category Definitions from Common Reference Databases

Race/Ethnicity Collection Method	Asian	Black	HA/PI	NA/AN	White	Multi-racial	Hispanic	Non-Hispanic
SEER Varies by State cancer registry	Req	Req	Req	Included in Asian	Req	Req	Req: Not mutually exclusive of race	Req: Not mutually exclusive of race
US Census Self-identified	Req	Req	Req	Req*	Req	Two or more races	Req: Not mutually exclusive of race	Req: Not mutually exclusive of race
CTEP Varies by protocol or cancer center	Req	Req	Req	Req**	Req	Not Req	Req: Not mutually exclusive of race	Req: Not mutually exclusive of race
State Registries varies	Varies widely in all categories							

*Requires tribal name/enrollment

**Includes C. and S. American natives

Excluded Subjects

- Multiracial subjects may be excluded or classified as “other”
- Patients with unknown race or no answer for race
 - Most intake databases do not force an answer to race/ethnicity

Frequency of Reporting

5 year intervals *are not useful* when evaluating recruitment and retention interventions.

- Balance frequency of reporting with sample size
- Staffing issues: are there enough staff to validate and analyze data?
- Is the period of data collection long enough to see trends?
- Is the period of collection long enough to yield enough subjects for significance?

Summary

- Each institution
 - may define its own catchment area
 - may choose how to collect patient race and ethnicity information
 - may choose how to report patient race and ethnicity
- It's important to know how your institution collects this information and the strengths and weaknesses of its processes.