

Terminology for the Reconsideration of Absolute Neutrophil Count Reference Ranges by Duffy Status

Formal Project Title: Reconsideration of Absolute Neutrophil Count Reference Ranges by Duffy Status

Short Project Title: ANC by Duffy Status

Terminology Guidance

In order to maintain accuracy, consistency, and sensitivity in our communications related to the project, we provide the following guidance on the usage of specific terminology:

Duffy-null:

- Use "Duffy-null" when referring to individuals with the genetic variation in ACKR1 resulting in the non-expression of the Duffy antigen on red blood cells. E.g. Individuals with the Duffy-null phenotype

Duffy-null phenotype:

The "Duffy-null phenotype" refers to the absence of the Duffy antigen on red blood cells due to genetic variation in ACKR1

Duffy non-null:

- Use "Duffy non-null" when referring to individuals with the Duffy positive or Duffy heterozygous (Duffy a positive or Duffy b positive) which collectively are phenotypes that are not associated with lower ANC.

Duffy status:

- Use "Duffy status" when discussing the genetic status related to the presence or absence of the Duffy antigen on red blood cells. E.g. ANC by Duffy status

DANC:

- "DANC" stands for "Duffy-null associated neutrophil count." which describes the clinically insignificant lower absolute neutrophil count (ANC) observed in individuals with the Duffy-null phenotype. This is preferred over the old terminology "benign ethnic neutropenia".

ANC:

- "ANC" stands for "absolute neutrophil count." a measure of the number of neutrophils in the peripheral blood and an important component of the complete blood count (CBC).

Respectful Language Principles:

1. **Do not treat Duffy status as a primary facet of identity:** Avoid categorizing individuals primarily by their Duffy status (e.g., Duffy individuals) and use language such as "individuals with the Duffy-null phenotype" instead.
2. **Do not refer to individuals who are Duffy-null as patients:** Use neutral terms like "individuals" or "participants" instead. Avoid terms that suggest it is an illness.
3. **Do not imply Duffy status is a disease state:** Emphasize that the Duffy-null phenotype is a genetic variation, not a disease.
4. **When referencing populations, discuss prevalence by using geographical distribution or genetic ancestry rather than race:** Race is a social construct and not a biological fact.

When discussing frequency of the Duffy-null phenotype, avoid using race alone. Rather, describe evolutionary pressures that resulted in the Duffy-null phenotype in malarial endemic regions in Sub-Saharan African and the Arabic Peninsula which resulted in those of certain genetic ancestries to be more likely to have the genetic mutation in ACKR1 resulting in the Duffy-null phenotype. Acknowledge the imperfections of this system and efforts to move away from overreliance on race and ethnicity alone and towards genetic drivers instead.

By adhering to these guidelines, we ensure that our communications are both accurate and respectful, promoting understanding and sensitivity within our project and the broader community.