

Patient Diversity and IBD Research Design

- Black, Asian, and Hispanic patients are substantially underrepresented in clinical trials, relative to the US population
- Up to 40% of IBD clinical trials from 2000-2010 did not report racial demographics
- Barriers to minority enrollment in clinical trials include
 - Geographic lack of access
 - Historical mistrust of medical trials
 - Lack of time or required technologies
 - Investigator bias
- Very little data regarding racial and ethnic differences in disease management and outcomes
 - Small trials, often with conflicting results

Racial and Ethnic Differences: Disease Characteristics

- Clinical studies have found
 - More extensive distribution of inflammation in Black, Hispanic, and Asian patients with CD, relative to White patients
 - ↑ Strictureing or penetrating disease in Black patients with CD, relative to White, Hispanic, or Asian patients
 - ↑ Perianal disease in Black and Hispanic patients with CD, relative to White patients
 - More extensive inflammation in White patients with UC, relative to Black and Asian patients
 - Black patients more likely to have proctitis or left-sided colitis

Racial and Ethnic Differences: Markers of Care

- Clinical studies have found
 - ↓ Specialist care and ↑ ED visits for Black patients relative to White
 - ↑ IBD-related hospitalizations for Black patients, relative to White and Hispanic
 - ↓ Use of biologics for Black, Hispanic, and Asian patients, relative to White
 - ↑ Surgical complications in Black patients with CD, relative to other races
 - ↑ Hospital readmissions in Black patients, relative to White

Racial and Ethnic Differences: Genetics

- > 200 alleles associated with risk of IBD; association varies with race¹
 - ↑ CD in East Asian individuals with *TNFS15* variants, but not in White individuals with these variants¹
 - ↑ CD complications, including stricturing disease, perianal fistula, and penetrating disease²
 - ↑ IBD associated with certain genetic variants only in people of African descent, although same variants are present in others³
- Variants mediating response to treatment vary with race^{1,3}
 - *TPMT* occurs more frequently in White patients, but is more closely related to thiopurine-induced leukopenia in Asian patients
 - *NUDT15* associated with thiopurine-induced leukopenia in Korean patients⁴

Socioeconomic factors (SES) and IBD

- Lower SES associated with¹
 - ↑ Health care utilization: hospitalizations, surgery, emergency department visits, outpatient visits
 - ↑ Relapse rates and IBD-related mortality
 - ↓ HRQOL
- Barriers to care, and barriers to clinical trial inclusion, include²
 - Reduced access to specialist care
 - Reduced access to expensive or time-consuming therapies (eg, infusions)
 - Lack of internet access
- Lower SES associated with multiple factors that impair health status²
 - eg, food insecurity, social support