Welcome!

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Centers for Disease Control and Prevention
WG Members*

- Hematologists: Tyler Buckner, Nathan Connell, Roshni Kulkarni, Beth Warren
- Nurses/Nurse Practitioners: Chris Guelcher, Susan Lattimore
- Social Workers & Psychologists: Lucy Ramirez, Emily Wheat
- Physical Therapists: Cindy Bailey, Pattye Tobase, Lena Volland
- Public Health: Judith Baker, Melissa Creary, Alexis Dinno, Keri Norris
- Patients/Caregivers: Esmerelda Vasquez, Randall Curtis, Michelle Kim, Mark Skinner
- Government: Vanessa Byams, Kathryn McLaughlin
- Industry: Susan Symington

* Some individuals above are members of >1 group
Health Services Research – priority research questions

Focus on:
• Access to care and services
• Quality of Care
• Satisfaction
• Costs
• Clinical and health related quality of life outcomes (including development of patient-reported outcome measures)
Diversity, Equity, Inclusion – priority research questions

- Identifying conscious and unconscious biases present within HTCs
- Understanding the lived experience of marginalized and minoritized populations
- Barriers and facilitators to accessing clinical care and research opportunities
- Mitigating individual provider behaviors, clinical and organizational structures, and other systems in place that hinder equitable delivery of care and services
- Engaging in active partnership with marginalized and minoritized populations in surveillance, research, and educational programs

Marginalized and minoritized populations may be characterized by:
- race, ethnicity, sex, gender identity, sexuality, age, income, disability status, language, culture, faith, geographic location, and country of birth
Implementation Science – priority research questions

- What HTC characteristics lead to higher rates of adherence to prophylaxis?
- Identify HTC characteristics that increase adoption of evidence-based behavioral health interventions.
- Assess and promote health equity and anti-racism within organizations / institutions.
- Enhancing cultural relevance of interventions to specific populations or settings.
- Using existing resources / data to assess guideline-concordant care.

Incorporate implementation outcomes into clinical studies – encourage / support / require hybrid study designs.
Outcome of work

• In many cases, priorities identified in our 3 areas of research are NOT questions, but rather areas of emphasis for future programs

• Group concluded that massive recruitment / educational efforts / training initiatives will be required to shift our field to encompass these areas of work

• WG members identified a shared sense of purpose:

  We see a critical need to continue work in these areas, across all bleeding disorders, particularly with respect to advancing diversity, equity, and inclusion initiatives in the bleeding disorders community
Thank You!