

Welcome!



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders



Judith Baker, DrPH, MHSA
Center for Inherited
Blood Disorders



Tyler Buckner, MD, MSc
University of Colorado,
Anschutz



Vanessa R. Byams, DrPH, MPH
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

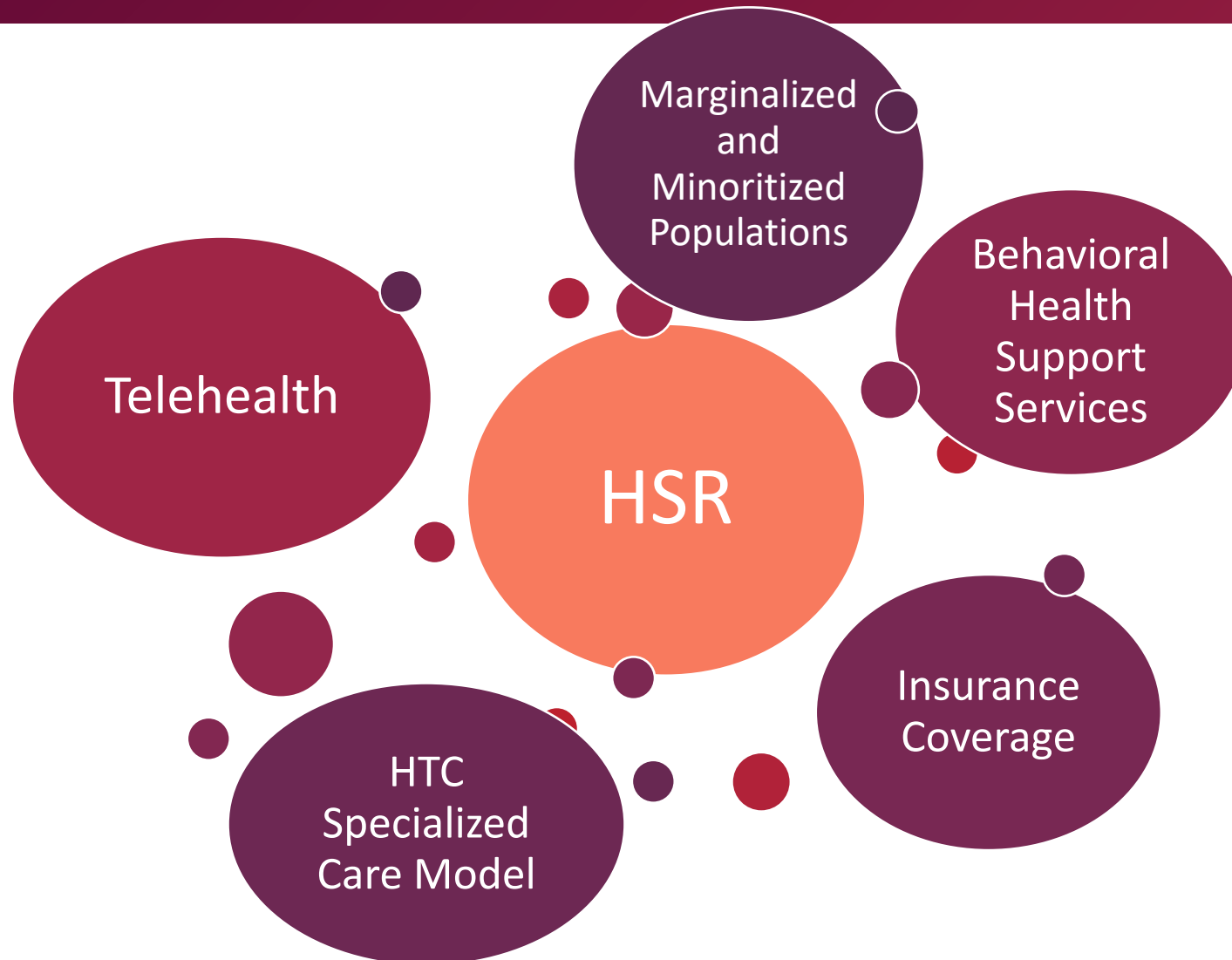
* Some individuals above are members of >1 group



Health Services Research – priority research questions



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders



Focus on:

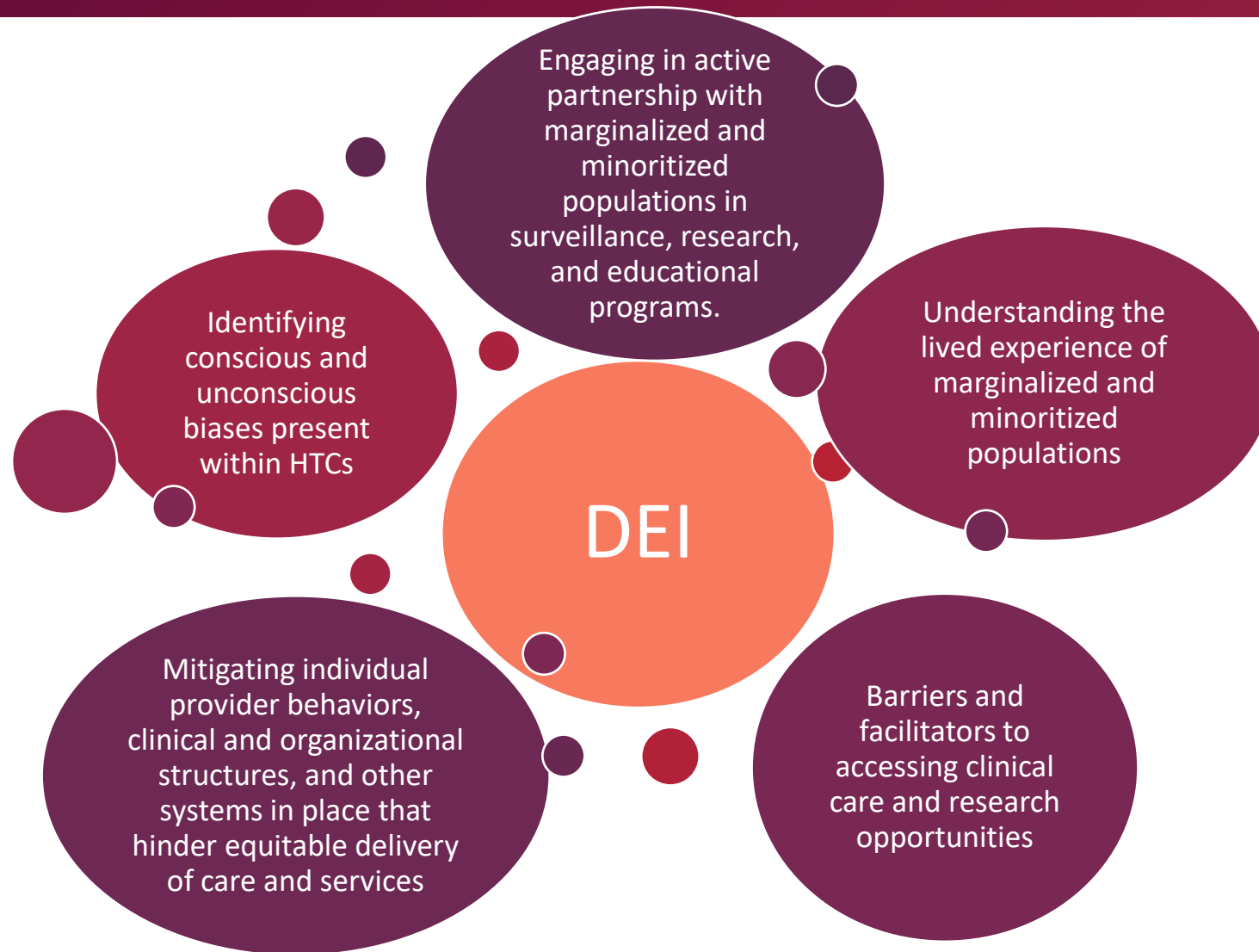
- Access to care and services
- Quality of Care
- Satisfaction
- Costs
- Clinical and health related quality of life outcomes (including development of patient-reported outcome measures)



Diversity, Equity, Inclusion – priority research questions



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders



Marginalized and minoritized populations may be characterized by:

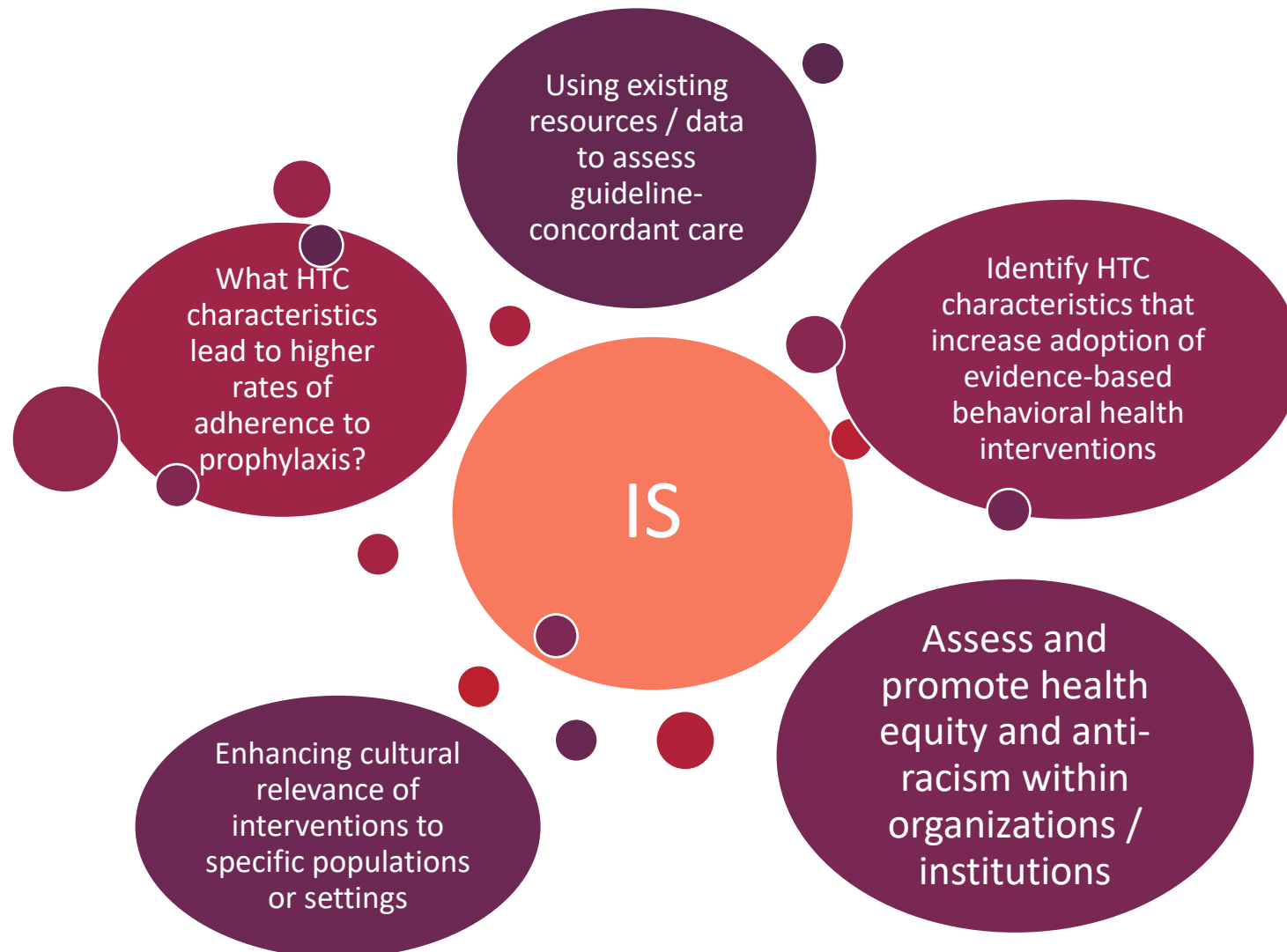
- race, ethnicity, sex, gender identity, sexuality, age, income, disability status, language, culture, faith, geographic location, and country of birth



Implementation Science – priority research questions



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders



Incorporate implementation outcomes into clinical studies – encourage / support / require hybrid study designs



Outcome of work



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

- 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





NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

Thank You!

