Building the Blueprint
March 2022 - Workshop

Working Group 4
Women, Girls, and Persons Who Have or Have Had the Potential to Menstruate
Welcome!

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Our Working Group
Focused research domains

- Uterine physiology and bleeding
- Bone/Joint
- Pregnancy
- Healthcare Delivery
- Sex/gender and lifespan biology
- mechanism of disease
  - diagnostics/screening
  - therapeutics
  - clinical trials
  - PROs and QOL
  - advocacy
  - collaborations
Foundational research gaps

- Norms and standards
- Phenotype prevalence
- Bleeding measurement
- Patient centered outcomes
Sex/gender lifespan biology

Hemostatic levels, reference ranges, PK/PD

- Genotype impact
- Bleeding disorder phenotypes
- Comorbidities
- Aging and menopausal transition
- Aging and pubertal transition
- Gonadal steroid hormones

High cost = lower feasibility
High downstream impact
Patient-reported outcomes, Quality of life

- Mental health
- Gender identity
- Sexual health
- Reproductive choices
- Menstrual bleeding patterns
- Symptom correlations (HMB and pain)
- Health behaviors
- Healthcare utilization
- Recreational engagement
- Educational and vocational goals
- Parenting experiences
- Family and relationships

High feasibility
Moderate to high impact
Possibly some risk
Pregnancy and postpartum

High cost = lower feasibility
High downstream impact
Some risk concerns

- Hemostasis mechanisms
- Hemostatic factor levels, reference ranges, PK/PD
- Hemorrhage prophylaxis and treatment
- Bleeding disorder workup
- Placenta and neonatal immune tolerance
- Prenatal diagnosis
- Neonatal diagnosis
Uterine bleeding

High cost = lower feasibility
High impact
Low risk

Blood loss quantitation

Relative effectiveness and dosing of therapies

Endometrial or novel drug delivery
Uterine hemostasis mechanism
Histopathologic diagnostic strategies
Hormone therapy impact on symptoms, workup
Drug interactions/combined therapies
Impact of factor, antifibrinolytic, DDAVP
Procedure safety and effectiveness (D&C, ablation, IUD, biopsy)
Hemostatic factor levels

High cost = lower feasibility
High impact
Low risk
High feasibility
Uncertain impact
Low risk

- Prevalence of subclinical joint bleeds
- Role of gonadal steroid hormones
- Biomechanical differences based on sex/gender
- Relationship with bone density
- Methods of assessment
- Affected joints
- Collagen impact on phenotype
Screening and referral

Varying feasibility
High impact
Low risk

Screening tools throughout lifespan
Time to diagnosis
Interdisciplinary integration
Transitions
Care models
Costs
Foundational research gaps

- Phenotype prevalence
- Bleeding measurement
- Norms and standards
- Patient centered outcomes
Potential Collaborators

American College of Obstetrics and Gynecology
Contraceptive Clinical Trials Network (CCTN)
Maternal Fetal Medicine Units Network (MFMU)
Foundation for Women and Girls with Blood Disorders (FWGBD)
American Thrombosis and Hemostasis Network (ATHN)
Hemostasis and Thrombosis Research Society (HTRS)
FIGO Committee for Menstrual Disorders
ISTH SSC Womens Health Issues in Thrombosis and Haemostasis
NIH-Advancing NIH Research on Health of Women
Obstetric Fetal Pharmacology Research Network
CDC Office of Women’s Health